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## **Community nurses' perspectives and experiences of the chronic oedema 'on the ground' education programme: a focus group study.**

### **INTRODUCTION**

Chronic oedema is a debilitating, enduring condition connected with several chronic conditions, lymphoedema, obesity and immobility (Todd, 2013). It is characterised by atypical swelling lasting for more than three months. Those affected may experience skin changes, recurrent cellulitis, superficial ulceration, exudate, lymphorrhoea, enduring pain and discomfort (Todd, 2013). The adverse impact of chronic oedema on an individual's health, well-being, everyday functioning, sense of self and quality of life may be lasting and profound (Williams et al, 2004; Franks et al, 2006; Symvoulakis et al, 2010; Okajima et al, 2013).

Chronic oedema affects 3.99:1000 of the population (Moffatt & Pinnington, 2012). However, prevalence may be underestimated because chronic oedema is infrequently recognised by healthcare professionals and the public (Todd, 2014). It is anticipated that prevalence will increase with population ageing and rising obesity (Todd, 2013).

The impact of chronic oedema management on community nurses' work is immense (Benson et al, 2016). Ineffective prevention and management are significant issues. Patient outcomes could be enhanced with appropriate management (Ashby et al, 2014). Yet inadequate knowledge and understanding of chronic oedema prevention, early recognition and effective management amongst healthcare professionals is of international concern (Stout et al, 2012; Keast et al, 2014). Moreover, whilst it is vital that healthcare professionals' possess the requisite capability to develop, improve and ensure safe and effective practice, austerity

measures continue to have a negative impact on access to continuing professional education (Greatbach, 2016). Consequently innovative, efficacious and flexible solutions to continuing professional education are required. To educate and support community nurses in managing chronic oedema, Lymphoedema Network Wales (LNW) conceived and developed an 'on the ground' education programme (OGEP). [Table 1].

**[INSERT TABLE 1 HERE]**

This paper will present findings from an independent evaluation which sought to determine the impact of the OGEP on community nurses, their management of chronic oedema and perceived benefits for their patients after engagement in the programme. LNW commissioned Swansea University to evaluate the OGEP.

## **METHODS**

Evaluating the effectiveness and practice impact of healthcare professionals' education is extremely complex and challenging (Clark et al., 2015). For the evaluation reported here focus groups (Kreuger & Casey, 2008) were used. Focus groups on a defined topic are ideal for examining experiences (Kitzinger, 1994). Collective discussion can generate rich data which may not be otherwise obtained, including valuable insights into context, processes and outcomes.

Purposive sampling was used to recruit community nurses working in three localities in Wales who could share their experiences of the practice impact of the OGEP. Access was granted by each locality's lead practitioner who also recruited the participants. Inclusion criteria were that participants had engaged with the OGEP and worked with patients living with chronic oedema.

The study was approved by Swansea University's research ethics committee and the Health Board's Research and Development office. All participants gave written informed consent and confidentiality was established and assured.

Three focus group interviews with 12 participants were conducted in 2016 by an experienced focus group researcher who was not known to participants. The focus groups lasted approximately 45 minutes and were digitally recorded. Discussion was aided by a loose interview guide derived from the literature and expert advice.

The data generated was analysed using Clarke and Braun's (2014) thematic analysis framework. Interviews were transcribed into Word® documents and all identifying features removed. To ensure accuracy transcripts were read while simultaneously listening to corresponding recordings. The transcripts were repeatedly read to ensure familiarity and deep understanding of the data and manually coded.

## **FINDINGS**

Twelve community nurses participated in three focus groups. The Community nurses' experiences of the OGEP are reported here in two main themes: professional practice outcomes for community nurses and perceived benefits for patients.

### **Professional Practice Outcomes for Community Nurses**

Across all the focus groups participants' agreed that the OGEP improved their awareness, knowledge and understanding of chronic oedema management, thereby developing them professionally. Indeed, some expressed greater confidence to assess and manage chronic oedema, indicating that the programme had afforded them additional capability for practice. Nonetheless, reservations about aspects of care promoted in the OEGP were expressed.

In all focus groups participants agreed that the OGEP had improved their chronic oedema knowledge. Data suggests the OGEP raised nurses' consciousness of the importance of and strategies for preventing chronic oedema and its potential adverse effects:

*Megan: Prevention is better than cure. Before they get to the point where they require us going in for wound care and compression and things like that. It's getting that information into them [patients] before that happens.*

Nevertheless, participants' perceived that aspects of proactive preventative interventions and holistic care promoted in the OGEP were established, core components of everyday community nursing practice, professional norms and thus nothing new:

*Bethan: Giving dietary advice, elevating legs this is **nothing** new. (Emphasis original)*

*Seren: Lymphoedema have told us, educate patients, creaming (...). I don't think there's anything new to me about this.*

Moreover, in overstretched community nursing services the OGEP's drive to incorporate even more preventative care in terms of washing and moisturising lower limbs for all patients on their caseloads was considered challenging:

*Megan: We were only going in to give them B12 and it was 'right you need to start (Yeh) getting buckets now and washing all of their legs and carrying big heavy buckets. (...)*

*Bethan: We couldn't do that for every patient (...). We just haven't got the time or the resources to be going on and doing that we just can't do it, it's impossible.*

There was agreement across the focus groups that the programme had improved their knowledge of chronic oedema management:

*Anwen: The knowledge of lymphoedema, and what we can do about it and signposting [others nodding in agreement]*

**Interviewer: Ok**

Eleri : *I'm quite new in the community and it definitely helped me with, signposting like you say and just having, because there's so many different areas in the community that you can refer people on to but, but it's having that knowledge.*

Moreover, the new knowledge could be shared with patients:

Eleri: *It's [the programme] also given me knowledge to pass onto the patients as well cos some of the patients have said, 'oh well no one's ever told me this before'.*

Some participants expressed newfound confidence to change their practice in terms of chronic oedema assessment, bandaging and applying compression without dopplering:

Alys: *It did give me the confidence to try the different types of bandaging and it gave me an understanding of the difference in the way that they taught us to pad the leg out and reshape the lymph so I could understand it better.*

**Interviewer: How about you Jane?**

Jane: *It gave me the confidence to apply some compression without dopplering*

**Interviewer: Ok so applying compression bandaging without dopplering.**

Jane: *Using clinical signs rather than using the abpi [ankle brachial pressure index] indicators.*

However, some participants articulated that once the OGEP team had left the workplace they reverted to modes of familiar practice:

Megan: *We had them for a couple of weeks (yeh) and then they went, and then they're [gone]. Ok nothings really changed, everything's exactly the same.*

Anwen: *I think you can see it's going to subside back to where (Eleri: Yeah) it was (Eleri: Yeah)*

Indeed, most participants spoke purely about referring patients to lymphoedema services:

Mari: *I don't think it's made us any more able to deal with the problems (...) because (Sioned: yeh apart from refer on) we just refer on (Sioned: yeah). (Emphasis original)*

Nevertheless, knowing when and how to refer to specialist lymphoedema services was valued for it imbued a sense of doing something:

Anwen: *If you come across patients [with chronic oedema] and you think 'oh, I know' (...). You get that diagnosis rather than bouncing round the system thinking 'well whose gonna sort this patient out?'*

Whilst acknowledging improved awareness and knowledge of chronic oedema prevention and management, many expressed reticence to change practices:

Megan: *They were saying (...), say, a patient's got oedema, 'you can just put them in one layer of actico'. We wouldn't, I still wouldn't do that.*

Mari: *As for us being, physically intervening in the fact that that a patient's got swollen legs and doing as they do, which is compress, we wouldn't do that without dopplering.*

**Interviewer: So you would always Doppler?**

Mari: *Yeah.*

Doppler sonography was considered a vital component of chronic oedema management. Indeed, without Doppler sonography findings, the majority preferred to refer patients to tissue viability services:

Ruby: *I still look at some people now though and think 'oh I'd love to get a pair of stockings on them' but I haven't got the confidence to say 'yeh I am'. They haven't been dopplered. We'd have to refer to (names TVN) (yeh)*

Bethan: *The TVN. So really nothing's changed (No) (No) at all. We can't just change our practice (No) (No).*

Data indicated that by ensuring doppler sonography was performed participants' felt they were adhering to local protocols and assuring and maximising patient safety:

Mari: *The protocol with dopplering ..... it's very clear. We don't put people into any kind of compression unless they're dopplered and they're deemed fit to be in compression.*

Bethan: *All patients need doppler and then if you don't, can't get a reading you go to your TVN and you've got that guidance you've got that authority to say 'yes go ahead and put them into compression or not'.*

Nevertheless, despite some reservations about aspects of the OGEP, participants across all focus groups agreed that when applied in practice their new knowledge, skills and improved self-efficacy regarding chronic oedema management had conferred patients' benefits.

***There are definitely a lot of positive points: Perceived benefits for patients***

In all focus groups participants perceived that their engagement with the OGEP had benefited patients living with chronic oedema. Patient benefit was mostly perceived in terms of improved quality of life and self-management capability. The perceived benefits were attributed to the participants' application and sharing of new knowledge and up-skilling. Nevertheless, the magnitude of patient benefit was perceived to be variable and contingent upon patients' engagement with and support for self-management.

Participants in all focus groups agreed that engagement with the OGEP and the immediate practice-based knowledge and skills transfer made a positive difference to patients' quality of life. Improved awareness of chronic oedema was perceived to expedite prompt interventions and thus confer patient benefit by preventing complex problems. Furthermore, several participants articulated that the application of new approaches to compression therapy meant patients experienced less pain and discomfort, improved physical functioning, mobility and general satisfaction:

*Jane: They're more comfortable, in less pain (that's right) and they're mobile aren't they often, their legs aren't so heavy.*

*Ruby: She only had to go in the bandages for a week and she was back in her smaller size stockings.*

**Interviewer: How did she feel about that?**

*Ruby: She was really happy*

Knowledge transfer about compression therapy, improved self-efficacy and reflection-in-practice were perceived to enhance patients' understanding of chronic oedema and its management. However whilst the OGEP concept of video film prescriptions delivered via internet technology to support patient education and enhance chronic oedema self-management was applauded, participants' expressed



doubt about their efficacy. This was because many patients had impaired hearing and sight and some did not have access to computers:

*Alys: Some of our patients perhaps are a little bit hard of hearing cos I mean I've got really good hearing and I and I had to come up close so. On a small screen it [video prescription] isn't so good and obviously eyesight as well.*

*Megan: The majority of our patients are elderly so they they're not really they wouldn't have computers and or even if they do have them they wouldn't know how to access them [video prescriptions].*

Many participants agreed that their improved knowledge about compression garments and appliances enabled them to confidently encourage and support some patients to don compression hosiery independently. They perceived that this conferred patients' benefit because healthcare utilization could be reduced and discharge was even possible:

*Sali: We don't have to visit as much or we do discharge them with the compression hosiery and just leave the carer's to then manage the legs.*

Ultimately, many patients were perceived to have greater freedom:

*Alys: In compression stockings it can change their life really.*

*Seren: Especially if they've been coming down to the treatment room because sometimes their life is taken over by that room isn't it so obviously the time is more their time, that's because they're not coming to see us all the time.*

Having more time for themselves was perceived as life enhancing and transformational. This is encapsulated in the following words of one participant who explained the magnitude of effect for a patient who had been on her caseload for many years:

*Jane: She's thrilled, absolutely thrilled. She feels better and it's [oedema management] impacting on her family less.*

However, many participants recognised that despite the OGEP'S aim of promoting self-management, many patients, even if motivated to wear compression garments, still required practical assistance:

*Seren: She said 'oh there's some support hosiery here now Seren isn't there?' 'Yeah' I said 'right let's try it'. She said 'I don't know whether I'm gonna be able to manage Seren'. I said 'right ok let's give it a go' (....). So we tried it (...) and she said 'Seren well I think I might be able to manage it'. I said 'well let's just see how you go' (...). She said 'my husband always put my stockings on for me'. (Ahh) I know. And of course he's passed away so that's another thing: we've got to consider, whether they're able to do it, because it's not easy.*

*Mari: Some couldn't use the aid*

*Sioned: Aids. Some couldn't apply them [Compression hosiery] if they didn't have (yeah) care agencies going (yeah) in.*

## **Discussion**

This evaluation aimed to determine the impact of the OGEP on community nurses, their management of patients with chronic oedema and perceived benefits for patients. The OGEP innovation is important as chronic oedema prevalence is projected to rise placing additional pressures on overstretched community nursing services and healthcare systems. Furthermore, significant cuts to continuing professional development funding continue (McQueen, 2017).

The findings presented here provide valuable insights into the impact of the OGEP on community nurses' chronic oedema knowledge and practice and their perceptions of outcomes for patients. The data reveal that the OGEP programme raised community nurses' awareness, knowledge and understanding of chronic oedema, its prevention, assessment and management. This finding underscores the potential value of professional learning and development within the workplace, where, through co-participation, working, learning, knowledge acquisition and transfer can co-occur (Lloyd et al, 2014). It is an important finding given that previous studies have reported that people living with lymphoedema perceive that many healthcare

professionals have inadequate knowledge and understanding of the condition and its management (Sneddon et al, 2008; Davies, 2012; Watts & Davies, 2016). Moreover, while there is a dearth of research investigating community nurses' chronic oedema educational needs, recent research signalled a perceived need amongst generalist healthcare professionals for lymphoedema management education (Noble-Jones, 2016).

That community nurses' felt able to share new knowledge about chronic oedema with their patients is an encouraging finding. Information sharing and education alone are insufficient in generating and sustaining behaviour change and self-management (Kennedy et al, 2013). Nevertheless, community nurses' expressed confidence to share knowledge is a step in the right direction, particularly in terms of preventative care, behaviour change and supporting self-management.

However, the extent to which the new knowledge and learning has been retained remains uncertain. Moreover, the degree to which the OGEP engendered sustained practice change was perceived to be rather limited. Principal barriers to change were workloads and protocols. In the community nurses' world of an over stretched workforce juxtaposed against burgeoning complex demands, wide-ranging responsibilities and uncertainty following recent changes to the General Medical Service contract, many felt that some aspects of opportunistic health promotion and direct preventative care were, in their reality, overly ambitious and unrealistic. Yet for most it was the notion of compression therapy in the absence of doppler sonoraphy that was a step too far.

The true effect of the OGEP in terms of patient benefit is elusive as patients' experiences were not sought. Data suggest community nurses' found that the application of new knowledge meant oedema could be reduced and some patients could be discharged. Consequently some patients' quality of life improved. This is an important finding as chronic oedema is connected with substantially impaired quality of life (Greene & Meskell, 2016). Indeed, unrelenting pain, exudate and functional loss generate immense challenges, permeate social networks, restrict employment and everyday activities (Lam et al, 2006; Bogan et al, 2007; Vassard et al, 2010; Ridner et al, 2012; Watts & Davies, 2016).

The data suggest that community nurses perceived that through effective knowledge and skills transfer patients' experienced improved self-efficacy and that this enhanced their ability to self-manage chronic oedema. Enduring chronic oedema self-management is important to manage regional swelling, reduce the risk of complications, potential psychosocial ramifications and possibly healthcare use (Watts & Davies, 2016). However, this can be difficult, time-consuming and burdensome, particularly in the absence of additional support. Moreover, compression may be a visible reminder of an underlying condition and generate discomfort. This may negatively influence adherence with compression therapy. Certainly findings from a recent Cochrane review of compression in preventing venous ulcer recurrence revealed lower adherence with high compression hosiery (Nelson & Bell-Sayer, 2014). Moreover, reporting findings from their randomised controlled trial of the effectiveness of compression hosiery versus compression bandaging in venous leg

ulcer treatment, Ashby et al. (2014) unexpectedly found that participants' discomfort with hosiery led many to change their treatment.

### **Limitations**

The study was designed and completed within a tight timeframe. Findings reflect experiences of a small sample of self-selecting community nurses who engaged with a specific programme in one Welsh region at one point in time. It is probable individuals volunteered to participate because they wanted to share their experiences of the OGEP and its impact on their practices. Data were generated retrospectively and was thus vulnerable to recall biases. Views of other key stakeholders, namely, managers, educators and patients were not sought. The OGEP was comprised of several components. It is unclear which component was most effective in generating change.

### **Conclusions**

Community nurses play a pivotal role in chronic oedema management because of their holistic, relational contribution to individualised care and cross boundary working. This evaluation focused on a workplace education intervention designed to enhance chronic oedema management in primary care. The findings reported here provide a snapshot in time and illuminate the perceived benefits for community nurses and patients. However, the learning effect in terms of measurable, sustained change in practice and tangible patient benefit cannot be established, indicating the need for a robust longitudinal study involving key stakeholders. Areas for future investigation include sustainability of learning effect and disseminating the education to others involved with care of people living with chronic oedema in primary care, notably General Practitioners and social care workers.

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### Key Points

- Community nurses spend considerable their time caring for people with chronic oedema. The chronic oedema 'on the ground' education programme (OGEP) was designed to deliver education and support within the workplace thereby reducing the need for study leave.
- Independent evaluation identified that participants' perceived that the OGEP had enhanced their awareness, knowledge and understanding of chronic oedema and its management and afforded them additional capability for practice. Participants also perceived then the new knowledge was applied in practice some patients experienced enhanced quality of life.
- Findings appear to underscore the potential value of workplace learning supported by direct access to expertise. However to establish the learning effect in terms of a measurable change in practice and tangible patient benefit a robust, longitudinal study is required.

