

Social media and patient advocacy in lymphoedema care: a perspective piece with the Australian of the Year, South Australian Local Hero 2022

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Key words

Consumer advocacy, patient advocacy, social media, lymphoedema, patient empowerment

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Electronic health (eHealth) refers to modalities such as telehealth, social media, robotics and artificial intelligence, which are being used to transform the way patients and practitioners communicate (World Health Organization, 2019). Eysenbach (2001) defined eHealth as: “an emerging field in the intersection of medical informatics, public health and business, referring to health services and information delivered or enhanced through the Internet and related technologies.”

Alongside the wide adoption of eHealth is the promotion of inclusion of the lived experience of patients in health research, translation, and implementation. (Darley et al, 2021) The lived experience of patients broadly refers to the experiences of those on whom a social justice issue or combination of issues, has had a direct impact. A formal definition is: “Personal knowledge about the world gained through direct, first-hand involvement in everyday events rather than through representations constructed by other people” (Oxford University Press).

Abstract

Social media, an accessible and multifaceted eHealth modality, allows for virtual interactions and the rapid dissemination of health-related information by both patients and health practitioners. The perspective of a breast cancer survivor’s strategic use of social media for patient advocacy in lymphoedema care is explored. Monique Bareham’s 15 years of advocacy contributed to the establishment of a lymphoedema compression garment subsidy scheme in South Australia, increasing government and policy-maker awareness of lymphoedema. She was named the 2022 South Australian Local Hero for her outstanding service. Monique’s perspective on advocating through the lens of lived experience via social media offers insight into effective advocacy strategies.

Recognising health providers and patients “as partners that both make vital contributions to produce good health and to improve quality of life for patients, caregivers and family” is regarded as a successful strategy for effectively and authentically engaging patients (Greever-Rice et al, 2020). Social media, as a digital medium for communication exchange and information sharing, is one form of eHealth empowering patients to share their lived experiences (Mazza et al, 2022).

Social media encompasses online digital platforms or websites that enable users to create profiles, share content, connect with others, and engage in various forms of communication and interaction concerning health and healthcare topics. (Chen and Wang, 2021). Platforms, such as Facebook, Instagram, X (formerly Twitter) and LinkedIn, provide a variety of ways for users to engage in content and use the platforms for advocacy efforts (Chalmers and Shotton, 2016; Shahbaznezhad et al, 2021).

Telegram is primarily known as a cloud-based instant messaging service. Unlike traditional social media platforms that encompass a broader range of features like content sharing, profile creation, and

social networking, Telegram is primarily focused on enabling messaging and secure communication.

Research on social media and lymphoedema care is in its infancy. In an example of effective use, in a study by Omid et al (2020), Telegram was used to deliver educational content. A channel was created called “Lymphedema Self-Management Education.” Educational content was uploaded on the channel twice a week for 3 weeks and presented to the channel as 20 audio and photo messages at different times of the day. The intervention was found to positively impact quality of life for lymphoedema patients.

Further research on the quality of information shared through social media is required. A 2021 study by Tuğral et al on Instagram hashtags specifically for lymphoedema concluded that it was not possible to say that it was the right platform for engaging with individuals and obtaining information “due to the abundance of misinformation arising despite its easy accessibility”.

This highlights the needs for sharing of information by informed sources. This is where patient advocacy has a role because they can offer an expert perspective (Towle

Practice development

et al, 2014; Brickley et al, 2021).

There is little information on patient advocacy in lymphoedema. The authors were not aware of any other published perspective pieces on the strategic use of social media for lymphoedema patient advocacy at the time of writing.

Monique Bareham: Patient advocate

Monique Bareham was diagnosed with breast cancer-related lymphoedema in 2010 (Figure 1). Being under 40 years of age and otherwise fit and healthy when diagnosed with breast cancer, it was a shock when her arm and hand suddenly started to swell during chemotherapy. Monique stated, "I was more frightened of my lymphoedema than I was of my cancer."

Monique was diagnosed with stage two early lymphoedema by Prof Neil Piller (Flinders University). She had just over a litre of fluid volume difference between her right and left arms, and was told that lymphoedema was likely to be a lifelong consequence of the breast cancer treatment. Monique privately funded compression bandaging, which was effective in initially reducing the size of her arm, but without regular access to appropriate care and compression garments, her symptoms worsened.

Her journey as a patient advocate began when she realised that lymphoedema was a condition that lasted a lifetime and required compression therapy to stop the worsening of symptoms. South Australia (SA) was the only Australian jurisdiction at the time that did not have a government funded garment subsidy programme.

Monique stated: "Due to the financial toxicity of cancer treatment I could not afford compression garments or paying for treatments privately. I lost my job. All I could see was a life with a progressive chronic condition which I could not afford to manage. This was very frightening and isolating and led to a period of depression and anxiety which made me question why I bothered to survive the cancer treatment at all."

Monique began her advocacy journey in 2012 by joining the Lymphoedema Support Group South Australia (LSGSA). She quickly assumed leadership roles and became president of LSGSA in 2013. Monique also created the role of lymphoedema advocate in LSGSA,



Figure 1. Monique Bareham holding her award for South Australian of the Year, Local Hero 2022.

and held both positions until 2022. Her advocacy efforts were formally recognised as part of the prestigious Australian of the Year awards, where she was the 2022 SA Local Hero.

Methods

Monique used social media strategically to support her advocacy. Specifically, Monique concentrated her efforts with social media pages on Facebook (commenced in June 2015), Twitter/X, LinkedIn and Instagram. Monique also utilises her website www.lymphadvocate.com to record and blog about advocacy activities. Three examples of strategic use are described below.

Using social media to advocate to former Australian Minister for Health and Aged Care

Before the 2019 federal election, Monique learnt via social media that Health Minister Greg Hunt would attend a community forum in Mt Gambier, SA. She drove for 6 hours to attend and organised members of the Mt Gambier Breast Cancer Awareness Group to join her. Together they raised the issue of the lack of a compression garment subsidy with the federal health minister, the local federal member, and the local state member.

A post on Facebook after the event read: "Last night, Monique Bareham joined with Mt Gambier LSGSA and Breast Cancer Support Group members to attend the Mt Gambier Community Q and A Forum hosted by Federal Member for Barker - Mr Tony Pasin MP with Special Guest, Federal Minister for Health Mr Greg Hunt MP."

"Monique raised the lack of public lymphoedema services and a compression garment subsidy in Mt Gambier and Statewide. Monique also raised the concern that Lymphoedema Services have not been included in the Repat Master Plan even though Lymphoedema Services were listed as the No. 1 service missing in the initial proposal."

"Minister Hunt gave an undertaking to raise these issues with SA Health Minister Wade today acknowledging that there is a 'GAP' in lymphoedema services and subsidies in SA."

"We eagerly wait to hear the outcome of this meeting!"

Following this event, Monique launched a lymphoedema awareness campaign in March 2019, which included letters to all South Australian Parliament members and a targeted social media campaign. This advocacy prompted Member of the Legislative Council (MLC) Ms Connie Bonaros to reach out and facilitate a roundtable meeting on 10 May 2019, with the SA Health Minister and representatives from SA Health and LSGSA. This meeting resulted in the establishment of the South Australian Lymphoedema Compression Garment Subsidy Scheme Advisory Group and a working party, tasked with launching the subsidy program in July 2020.

Public service delivery promotion in a rural town

Monique stated, "I am a firm believer in 'Nothing about us, without us', which means consumers must be front and centre and meaningfully engaged in all elements of health provision and health and medical research."

On 12 August 2023, a free lymphoedema patient information and screening day was held in the rural town of Whyalla, SA, organised with the support of the Whyalla Pink Spirits Breast Cancer Support Group, led by Rae Williams. The event was attended by Monique, Prof Piller, Toni Piller, Andrea Mangion, Dr Vani Prasad, Lymphoedema Association Australia (LAA) members, representatives from garment companies, 30 health professionals, and 90 patients. Monique used social media before and after the event to raise awareness of a gap in public service delivery of lymphoedema services in the local area (Figure 2). Following the event, she met with Local Federal and State Members to discuss the issue which assisted in prioritising the training of a new lymphoedema practitioner in the local area



Figure 2. Whyalla Lymphoedema Expo Facebook post including the Whyalla News article on the event.

to enable the support of public patients.

Awareness of lymphoedema through public QR codes

Monique was chosen to be one of the 100 power portraits for the 2024 SA history festival [Figure 3]. The theme was “power” and Monique chose to use this unique opportunity to help destigmatise the wearing of compression garments for lymphoedema and send a message that with the right treatment and support individuals affected by lymphoedema can live a healthy and productive life. On a public street power pole (referred to in SA as a “stobie pole”), portraits of Monique wearing garments were displayed with a QR code that linked to Monique’s patient advocacy message. Social media posts encouraged commenting, sharing and engaging with the QR code.

The message was: *“I think you never really know the power you have within yourself until you are faced with a personal crisis. For me the collateral damage caused by my cancer treatment left me totally depleted and devastated to the point that I questioned why I had bothered to endure it. It was in the re-inventing of myself as a lymphoedema patient advocate that I truly learned how much power I held within myself to rebuild and shape who I wanted to be. As I learned more about the suffering of others I was further strengthened.*

Each interaction galvanised my resolve to do my best to improve the health outcomes for other affected by lymphoedema, including normalising and destigmatising garments and building recognition and awareness.”

During the campaign, members of parliament directly reached out to Monique.

One comment on Facebook and Instagram by Connie Bornaros (MLC)

read: *“Proud to see Monique Bareham – Leading Lymphoedema Advocate 2022 SA local hero, feature on Welbourne Street in Mitcham as part of SA histories festival. Through this initiative she hopes to raise awareness and foster understanding about the importance of compression garments for many individuals. Monique’s words resonate deeply.”*

Discussion

Monique’s perspective highlights the value of consumer and community advocacy for improved lymphoedema care, with social media serving as an effective eHealth tool. The approach of involving community members is supported at a national level. The National Health and Medical Research Council (2024) states it understands “the importance of engaging with consumers and the community on its role and activities, whilst also providing leadership and guidance to the health and medical research sector on the meaningful engagement of consumers throughout all stages of research and health care.”

Fifteen years after Monique’s lymphoedema diagnosis, her condition is well managed, but lymphoedema remains a constant reminder of her breast cancer treatment and the initial struggles she faced in sourcing necessary compression garments.

Compression therapy has been shown to be necessary for lymphoedema, not only



Figure 3. Monique with her mother (Ursula Legierski) at the Welbourne Street stobie pole.

through maintaining limb volume measures but also through decreasing the incidences of cellulitis (Webb et al, 2019; Grunwald et al, 2021). In Australia, government-funded garment subsidy programmes aim to reduce hospitalisations for cellulitis. The Agency for Clinical Innovation (2018) noted that two sets of custom-made compression garments cost only 14% of a typical hospital admission for lower limb lymphoedema, highlighting their cost-effectiveness. However, access to garment subsidy schemes varies across jurisdictions, leading to inequalities in types, quality, and eligibility for compression garments. In July 2020, after years of advocacy, the South Australian government announced a subsidy programme for compression garments, dedicating millions of public health dollars to support South Australians with lymphoedema (Government of South Australia, 2024).

Monique's efforts, along with other patients and other stakeholder organisations advocating over many years for lymphoedema patients, made this achievement possible.

Conclusion

Further research on the impact and benefits of social media and patient advocacy

for patients living with lymphoedema is required. This perspective piece highlights the value of consumer and community involvement in influencing government and policy-maker awareness of lymphoedema and how social media can be an effective tool to amplify the patient voice.

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