

Living with a chronic wound — an update of an ongoing project by the European Wound Management Association



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Chronic wounds have an impact on the activity of daily living of patients and their families. They also represent a significant challenge for care providers. To demonstrate what it means living with a chronic wound, the European Wound Management Association (EWMA) initiated a project, which used short video sequences to illustrate the experiences of patients living with a chronic wound, the experiences of healthcare professionals providing wound care and to give a voice to representatives from healthcare institutions. A total of 37 video sequences with nine patients, six carers and 20 healthcare professionals within five European countries were conducted. The results showed that patients experienced a good relationship and communication with the healthcare professional and they were confident their wounds would heal rapidly. It can be concluded that the EWMA project helped to better understand what it means living with a chronic wound, as well as what standard of care is required.

Chronic wounds, such as leg ulcers and diabetic foot ulcers, occur in many patients with vascular disease or diabetes (Frykberg and Banks, 2015). These ulcers persist for an average of 12 to 13 months, recur in up to 60% to 70% of patients, can lead to loss of function and decreased quality of life, and are a major cause of morbidity (Frykberg and Banks, 2015). About 1% to 3% of the population in industrialised countries suffer from a chronic wound (Posnett et al, 2009). The World Wound Management Forecast to 2024 estimates a yearly increase of the incidence of venous leg ulcers and pressure ulcers by 6% to 7% and diabetic foot ulcers by 9%. The cost of care for those conditions is an estimated 2% to 3% of all health expenditure in developed countries (Posnett et al, 2009).

Over the past decade, there has been an increased focus on patient-reported outcome measures in wound care. Through this, a better understanding of the effects of chronic wounds on quality of life can be fostered and wound care professionals can deduct interventions for a more holistic care, while improving patient outcomes.

Living with a chronic wound affects quality of life not only for the patient, but also for the family. This topic has been studied mainly in patients with venous leg ulcers and includes physical, psychological and social aspects (Phillips et al, 2018). An integrative review conducted by Gonzalez-Consuegra and colleagues (2011) showed that living with a leg ulcer has a strong negative impact on people in many areas of their lives, such as mobility, or body image. Several other studies confirm this affirmation (Herber et al, 2007; Kapp et al, 2018; Marczak et al, 2019). Pain is described as the most limited symptom in people living with a leg ulcer (Wissing et al, 2002; Palfreyman, 2008; Kapp et al, 2018; Phillips et al, 2018; Marczak et al, 2019).

Moreover, restricted mobility and sleep disorders due to the pain are also reported. People often complain about itching, odour and legs swelling. Phillips and colleagues (2018) in their systematic review of qualitative research highlighted that exudate and unpleasant odours associated with wounds have been named as the main cause of people's embarrassment when in society. These result

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in higher anxiety and depression scores and a modified body image (Phillips et al, 2018). Finally, people reported a negative emotional impact on their lives with symptoms such as anger, depression and social isolation (Kapp et al, 2018). These ulcers have an impact on quality of life in society.

To better understand what it means living with a chronic wound, the European Wound Management Association (EWMA) has initiated a project entitled 'Living with a chronic wound'. This project aims to illustrate with short video sequences a) the experiences of patients living with either a leg ulcer, a diabetic foot ulcer or a pressure ulcer; b) the experience of healthcare professional(s) providing wound care; and c) voices of representatives from healthcare institutions.

What have we done?

Firstly, EWMA has developed an interview guide for patients and healthcare professionals. The introductory question for patients was: "Can you tell me your story about your wound?" Additional questions were: "Is there anything related to the wound treatment/management you received that you did not like?" or "How do you describe your relationship between you and your wound care professional?" To know more about specific subjects, questions such as "Can you tell me more?" or "What does this mean for you?" were asked.

Secondly, EWMA developed an interview guide for wound care professionals and healthcare institutions. The focus of these questions centred around the challenges when treating patients with wounds; the challenges related to the communication with the patient; how successful evidence-based practice is lived in the specific hospital and how the relationship and/or collaboration between patients and healthcare providers look like. Filmmaker and storyteller Aurora Piaggese conducted 37 video interviews with nine patients, six carers and 20 healthcare professionals in the Czech Republic, Finland, France, Switzerland and the UK during a 3-week period. The filming took place either in the outpatient clinic or in the patients' homes. The videos have been cut and all sequences have been subtitled in English. Before recording the videos, patients and healthcare professionals provided their consent.

What are the stories?

All patients spoke of having a good relationship with their current specialists (with the

nurses especially) and were happy about the communication that exists between them. All patients explained that healthcare professionals were taking time to listen to their problems. Eight patients highlighted that they were convinced that their wound had closed rapidly and were happy to share their experiences. Only one patient mentioned feeling isolated, discriminated against and feeling desperate because of their condition. Five patients spoke of experiencing one or more recurrences. They experienced emotional problems due to the recurrence of the wound. Two out of nine participants described their situation as currently improving in relation to what they had experienced in the past.

All the carers described an admiration for the courage and strength of their loved ones and admitted to have felt despair in the past. All of them felt positive about the future.

All of the healthcare professionals involved in the videos highlighted that they try to provide optimal care for their patients and their families. Their overriding wish was having more time for direct patient care. Having direct access to the newest guidelines and having an effective network was also highlighted as being very important.

What will be the strategies to engage stakeholders and disseminate the information?

The collected stories will be published during the 2019 EWMA conference, which is held in Gothenburg, Sweden, between June 5–7. Additionally, the following dissemination is planned:

- Website: the collected stories will be published on the EWMA website and, therefore, will provide information to the professional and scientific community, as well as to the public.
- Publication. Project findings and recommendations will be published in scientific and professional journals and made available to the scientific and professional community.
- Clinical guidelines. The results will inform future EWMA position documents. In addition, they will serve as recommendations in guidelines and will assist the facilitation of the dissemination.
- Education materials. The education committee of the EWMA will include the results in the e-learning modules. Additionally, the results will support the development of wound outpatient

posters, reference cards and consumer brochures, which should be effective tools for disseminating study findings and recommendations. Consumer brochures will educate the public and provide the necessary information to encourage patients to speak to their physician regarding their management.

- Slide presentations. Slide sets will be put together to provide project results and implications. These will be available for formal presentations, departmental seminars or local wound care society meetings. A set of slides will also be developed for presentation to patients who will receive a summary of the project findings, recommendations, relevant articles, cost-effectiveness information and strategies for implementation to improve wound care.

It can be concluded that the use of video material in the EWMA project helped gain a better understanding of patients' experiences of living with a chronic wound, as well as determining the elements needed for

healthcare professionals to provide effective wound care. **WINT**

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