



How does a chronic wound change a patient's social life? A European survey on social support and social participation

Toni Maria Janke¹  | Vlastimil Kozon² | Marjam Barysch³ |
 Skaidra Valiukeviciene⁴ | Laura Rackauskaite⁴ | Adam Reich⁵ |
 Katarzyna Stępień⁵ | Monika Jankechova⁶ | Catherine van Montfrans⁷ |
 Stella Amesz⁸ | Elena Conde Montero⁹ | Matthias Augustin¹  |
 Christine Blome¹

¹Institute for Health Services Research in Dermatology and Nursing (IVDP), University Medical Center Hamburg-Eppendorf (UKE), Hamburg, Germany

²Society Wound Diagnosis and Wound Management Austria, Vienna Medical Academy, Vienna, Austria

³Department of Dermatology, University Hospital Zurich, Zürich, Switzerland

⁴Department of Skin and Venereal Diseases, Lithuanian University of Health Sciences, Hospital of Lithuanian University of Health Sciences Kauno Klinikos, Kaunas, Lithuania

⁵Department of Dermatology, Institute of Medical Sciences, Medical College of Rzeszow University, Rzeszów, Poland

⁶Faculty of Health and Social Work St. Ladislav in Nove Zamky, University of Health and Social Work St. Elisabeth in Bratislava, Bratislava, Slovakia

⁷Department of Dermatology, Erasmus Medical Center Rotterdam, Rotterdam, The Netherlands

⁸Department of Health Sciences, Section of Nursing Science, University Medical Center Groningen, University of Groningen, Groningen, The Netherlands

⁹Dermatology, Hospital Universitario Infanta Leonor y Virgen de la Torre, Madrid, Spain

Correspondence

Toni Maria Janke, Institute for Health Services Research in Dermatology and Nursing (IVDP), University Medical Center Hamburg-Eppendorf (UKE), Martinistraße 52, 20246 Hamburg, Germany.

Email: t.janke@uke.de

Funding information

European Academy for Dermatology and Venereology (EADV)

Abstract

Chronic wounds can severely limit patient's social life. This cross-sectional study investigated quantitatively social support of patients with chronic wounds, its association with health-related quality of life as well as qualitatively changes in social participation of these patients. Overall, 263 patients from seven countries participated. The most frequent wound class was leg ulcer (49.2%). Results revealed generally high levels of social support (mean global score: 5.5) as measured with the Multidimensional Scale of Perceived Social Support. However, individuals differed considerably (range 1.0–7.0). All dimensions of social support differed by patients' family and living situations ($p < 0.001$ to $p = 0.040$) and were positively correlated with generic health-related quality of life ($r = 0.136$ – 0.172). Having children, living with others and being in a relationship were significant predictors of having higher global social support. Patients reported great support from family members. Many participants reported no changes in relationships with friends. Wound care managers took an important role and provided additional emotional support.

This is an open access article under the terms of the [Creative Commons Attribution-NonCommercial](https://creativecommons.org/licenses/by-nc/4.0/) License, which permits use, distribution and reproduction in any medium, provided the original work is properly cited and is not used for commercial purposes.

© 2023 The Authors. *International Wound Journal* published by Medicalhelplines.com Inc and John Wiley & Sons Ltd.

Patients reported a range of discontinued activities. Despite the high overall level of social support, inter-individual differences should be acknowledged. The importance of family carers should be acknowledged to be able to reduce caregiver burden and to ensure high-qualitative wound care.

KEYWORDS

chronic wounds, quality of life, social participation, social support, wound-QoL

Key Message

- Chronic wounds with longer duration do not only show impaired healing and impact on patients' physical and mental health but pose more severe restrictions on patients' social lives, including social participation and social support.
- This study aimed to investigate social support and its associations with health-related quality of life as well as to explore changes in social participation of patients with chronic wounds in a European sample of patients with chronic wounds.
- Results reveal generally high levels of social support, though, large interindividual differences were detectable; all dimensions of social support differed by patients' family and living situations and were positively correlated with generic health-related quality of life.
- Patients reported great support from family members, also in wound care, and highlighted the significance of professional wound care managers for both wound care and emotional support.

1 | INTRODUCTION

Wounds that fail to heal in a timely manner or are caused by an underlying condition (e.g., venous insufficiency, arterial disease, diabetes, constant pressure) are referred to as chronic wounds.¹ A systematic review showed a worldwide prevalence of 1.67 per 1,000 people.² Prevalence rates are generally higher in older people.³ Considering the demographic change and the societal economic burden of chronic wounds,³ they are a rising issue in societies like the European Union.

The individual patient may be burdened by wound-specific symptoms, such as exudate, odour and wound pain⁴ but also by less wound-specific consequences, such as restricted mobility⁵ and long-lasting comorbidity.³ Chronic wounds can cause mental and psychosocial strain. Patients report sleep disturbances, anxiety and depression⁴ as well as impacts on their financial status and their everyday life activities.⁶

These aspects are covered by the subjective and multidimensional construct of health-related quality of life (HRQoL),⁷ which is well-established in clinical care and research. In routine care, HRQoL assessments support incorporating the patient into the care plan, especially in decision-making, priority-setting and monitoring.⁸ In clinical research, measuring HRQoL has been established

by regulatory authorities as an important endpoint in treatment benefit assessments.⁹

Chronic wounds with longer duration do not only show impaired healing¹⁰ but impact also more severely on patients' social lives, including social participation and social support.^{11,12} According to the model of Douglas et al.,¹³ social participation comprises social connections with other people, and informal and formal participation (i.e., activities pursued for own enjoyment or for others' benefit). Social participation has an effect on the individual's health, which is mediated by social support. Social support is the assistance or protection provided for a person and is based on reciprocity.¹⁴ In patients with chronic wounds, reports on social participation vary considerably.¹⁵ While some patients experience strong relationships, a great share of people with chronic wounds is socially isolated or is impaired in their social functioning. Many patients are not able to maintain their former social roles (e.g., as carer, as employee, or by pursuing leisure time activities) and become care dependents.^{16,17} When insufficient support is received from friends and family, patients might draw social support mostly from professional care providers. To remain this social support, patients might hinder their wound from healing.¹⁸ Though this is rather a rather anecdotal phenomenon, secondary illness benefits might be evident.¹⁹

There are indications that social support is lower in patients with chronic wounds than in controls.²⁰ In conditions other than chronic wounds, studies showed that increased social support is beneficial not only for patients' mental and psychosocial HRQoL but also for their physical HRQoL and health condition.²¹ In patients with chronic wounds, this has not been examined sufficiently.

Therefore, this study aimed to investigate social support and its associations with HRQoL as well as to explore changes in social participation of patients with chronic wounds.

2 | METHODS

This study draws on data from a project validating the Wound-QoL questionnaire in a European sample. The project was approved in June 2019 by the ethics committee of the Medical Association of Hamburg (PV7029); secondary ethical votes were obtained in all participating countries.

2.1 | Patients

Partners in seven European countries (Austria, Lithuania, Netherlands, Poland, Slovakia, Spain and Switzerland) recruited patients in their dermatological outpatient clinics. Inclusion criteria were having a chronic wound, age of at least 18 years, ability to understand and complete the questionnaire, and written informed consent.

2.2 | Data collection

Between October 2020 and November 2021, patients were asked to participate in the study during their clinic visits. Both patient and healthcare professional (doctor or nurse) completed a paper-based questionnaire. Social support was assessed using the Multidimensional Scale of Perceived Social Support (MSPSS).²² This patient-reported questionnaire contains 12 items with a 7-point Likert scale (from 1 'very strongly disagree' to 7 'very strongly agree'). Mean scores are calculated for the global scale and three subscales (family, friends and significant other; four items each). Patients also answered questions on sociodemographic and wound characteristics as well as the following patient-reported outcome measures (PROMs):

1. Wound Quality of Life questionnaire 17 item version (Wound-QoL-17); wound-specific HRQoL; scale ranges from 0 to 4; higher values indicate higher impairments in HRQoL⁶

2. Dermatology Life Quality Index (DLQI); 10 items; dermatology-specific HRQoL; scale ranges from 0 to 30; higher values indicate higher impairments in HRQoL²³
3. EQ-5D-5L (five items); generic HRQoL encompassing mobility, self-care, usual activities, pain/discomfort, anxiety/depression; higher values indicate higher HRQoL²⁴

For analysing the EQ-5D-5L, the index was calculated using the Spanish value set ranging from -0.501 to 1.000 ²⁵ as value sets are available for only a minority of countries participating in this study. Health care professionals provided information about wound characteristics.

In addition, patients in German-speaking countries (Austria, Switzerland) completed a short free-text survey asking for discontinued activities due to the wound, newly started activities since the occurrence of the wound, changes in relationships with family members, changes in relationships with friends, changes in relationships with other people, the importance of the person treating the wound.

2.3 | Data analysis

Descriptive characteristics were determined (mean, standard deviation, median, range for each item and scale, number and percentage of participants agreeing to each item). To analyse social support in more detail, we conducted bivariate subgroup comparisons using Chi-square tests for dichotomous group characteristics and analyses of variance (ANOVAs) for group variables with more than two groups. For multivariate analyses, we conducted logistic regressions with the MSPSS subscales as the dependent variable and the group variables from the bivariate analyses as independent variables. We applied the forward imputation method with an input threshold of $p = 0.10$ and an output threshold of $p = 0.20$.

Written answers to the free-text survey questions were analysed using qualitative content analysis according to Mayring.²⁶ For this, data were categorized and grouped into sub- and main categories.

To integrate quantitative and qualitative data, we grouped patients who completed the qualitative questionnaire into three groups: (1) patients reporting good social support (in at least one of the three questions asking for changed relationships with family, friends and others), (2) patients reporting little to no social support and (3) patients reporting unchanged relationships or whose responses were not sufficient for group assignment. For these groups, we analysed descriptive statistics of the

MSPSS scales. Additionally, we compared data on scale level between those being grouped as having good social support and those reporting little to no social support using Mann–Whitney U tests.

Statistical analyses were conducted using IBM SPSS Statistics for Windows (Version 27.0; Armonk, NY: IBM Corp); the significance level was set at $p = 0.05$. Qualitative analyses were conducted using MAXQDA 2022 (Berlin: VERBI Software).

3 | RESULTS

In the seven countries, 263 patients participated (sample characteristics, see Tables 1 and 2). Of these, 54.0% ($n = 142$) were male and the mean age was 69.3 (SD 13.8) years. Leg ulcers (i.e., *ulcus cruris venosum*, *ulcus cruris arteriosum* and *ulcus cruris mixtum*) were the most frequent wound class ($n = 150$, 49.2%) and, on average, the wound had been persisting for 26.1 months (SD 68.0, median 9.0).

Results of the MSPSS indicated on average a high level of social support with item and scale mean values between 4.9 and 5.9 (median: 5.0–7.0). Nevertheless, patients' responses differed considerably (range: 1.0–7.0; Table 3). Items on the *friends* subscale showed the lowest values with 63.8% to 65.5% agreeing to each statement, whereas agreement rates for the other items were between 78.8% and 85.0%. Subgroup analyses (see Table 4) showed significantly higher social support in patients being in a relationship ($p < 0.001$ to $p = 0.016$) and living with others ($p < 0.001$ to $p = 0.040$) for all scales. Additionally, having children was associated with higher global and family support ($p = 0.004$ – 0.033). Having a school-leaving certificate with university entrance ($p = 0.026$) and being employed ($p = 0.044$) were associated with higher support from friends. Age, sex and wound characteristics showed no differences in any of the scales. The MSPSS scales showed no significant correlation with any of the Wound-QoL-17 scales (Table 5). Higher reported support from the family correlated significantly with reduced dermatology-specific burden regarding the symptoms and treatment subscales (each $p = 0.011$) and higher support from a significant other correlated significantly with reduced dermatology-specific burden regarding symptoms ($p = 0.025$) in the DLQI. All MSPSS scales showed significant correlations with the EQ-5D-5L ($p = 0.008$ – 0.032) with higher support being associated with higher generic HRQoL.

Regression analyses (Table 6) showed that having children ($p = 0.002$), living with others ($p = 0.008$) and being in a relationship ($p = 0.043$) were significant predictors of having higher social support (MSPSS *global*

scale). Higher social support by the family was associated with living with others ($p < 0.001$) and having children ($p = 0.001$); EQ-5D-5L was included in the model but was not significant ($p = 0.082$). Better HRQoL according to EQ-5D-5L ($p = 0.035$) and being female ($p = 0.041$) were significant predictors for higher social support from friends. Living with others ($p = 0.006$), being in a relationship ($p = 0.010$) and having children ($p = 0.024$) were significantly associated with higher support from a significant other.

The qualitative free-text survey was completed by 47 patients from German-speaking countries. These patients were 67.6 (SD 13.6) years old and 70.2% ($n = 33$) were male. The most frequent wound class was diabetic foot ulcer (DFU; $n = 20$, 42.6%), followed by leg ulcer ($n = 11$, 23.4%). Most patients were not working ($n = 38$, 80.9%), lived in a relationship ($n = 24$, 51.1%), had children ($n = 34$, 72.3%) and lived with others ($n = 26$, 55.3%).

Patients' answers were categorized into five main categories: support from family; contact with friends and other people; the importance of nursing specialists; discontinued/restricted and new activities; limiting circumstances.

In the main category support from family, a great share of participants stated that family members provided wound care as well as emotional and everyday life support: *'My son takes care of me every day, looks after my wound. I appreciate his help and support'* (male, 89 years, leg ulcer). One patient stated: *'My wife assists me; without her I couldn't stay at home'* (male, 76 years, DFU). The majority of patients reported no changes due to the occurrence of the wound. In some cases, patients reported only few family contacts or not receiving sufficient support: *'The compassion in the family (consisting of husband and 2 sisters) is there, but no one can help'* (female, 84 years, other wound).

In the category contact with friends and other people, many participants reported no changes in these relationships: *'There have been no changes'* (male, 85 years, DFU); *'There have been no changes. I could not participate in the sporting activities'* (male, 67 years, DFU). Some expressed that they received emotional and everyday life support from friends: *'Friends also want to help me and encourage me being more active again once the prosthetic leg fits'* (male, 79 years, DFU). In contrast, others stated to have only few social contacts, partly due to the patient's high age, and others reported worsening relationships with friends: *'No social contacts possible as the quality of life is too limited!'* (female, 84 years, other wound); *'Contact with my group of friends has been reduced to the absolute minimum (Skype/phone/letters)'* (male, 59 years, other wound).

In the main category importance of nursing specialists, participants expressed how much they value the

TABLE 1 Patient sociodemographic and clinical characteristics (categorical variables).

Variable	Response options	N	%
Country	Austria	51	19.4
	Lithuania	50	19.0
	Netherlands	37	14.1
	Poland	50	19.0
	Slovakia	41	15.6
	Spain	21	8.0
	Switzerland	13	4.9
Gender	Male	142	54.0
	Female	120	45.6
	Missing values	1	0.4
Highest educational level	No certificate	7	2.7
	Certificate without university entrance	158	60.1
	Certificate with university entrance	70	26.6
	Other	22	8.4
	Missing values	6	2.3
Occupational status	Not working	224	85.2
	Working/in training	36	13.7
	Missing values	3	1.1
Family status	Single/separated/divorced/widowed	121	46.0
	In relationship/married	141	53.6
	Missing values	1	0.4
Having children	Yes	213	81.0
	No	48	18.3
Living situation	Alone	85	32.3
	With others (partner, children, other)	176	66.9
	Missing values	2	0.8
Living in a nursing home	Yes	24	9.1
	No	238	90.5
	Missing values	1	0.4
Wound class	Leg ulcer	111	42.2
	Diabetic foot ulcer	71	27.0
	Other	59	22.4
	Missing values	22	8.4
Wound slough	None	65	24.7
	Present (necrosis/fibrin)	190	72.2
	Missing values	8	3.0
Wound edge	Irritated	219	83.3
	Not irritated	39	14.8
	Missing values	5	1.9
Wound environment	Irritated	218	12.9
	Not irritated	39	14.8
	Missing values	6	2.3

(Continues)

TABLE 1 (Continued)

Variable	Response options	N	%
Odour	None	167	63.5
	Present	91	34.6
	Missing values	5	1.9
Amount of exudate	None	33	12.5
	A little	104	39.5
	Medium	89	33.8
	Strong	29	11.0
	Missing values	8	3.0

Abbreviation: N, number of participants.

TABLE 2 Patient sociodemographic and clinical characteristics (continuous variables).

Variable	N	Mean	SD	Median	Range
Age (years)	261	69.3	13.8	71.0	28–96
Working hours/week	32	35.3	11.8	40.0	8.0–60.0
Number of children	255	1.9	1.5	2.0	0–11
Wound size (cm ²)	245	40.6	96.1	9.0	0.1–900.0
Wound duration (patient-reported; months)	258	26.1	68.0	6.0	0.0–600.0
Wound duration (clinician-reported; months)	249	20.7	57.1	6.0	0.0–600.0

Abbreviations: N, number of participants; SD, standard deviation.

TABLE 3 Social support according to Multidimensional Scale of Perceived Social Support (MSPSS).

MSPSS items and scales	N	n (%) agree	Mean	SD	Median	Range
1 There is a special person who is around when I am in need.	260	79.6	5.7	1.8	6.0	1.0–7.0
2 There is a special person with whom I can share joys and sorrows.	259	83.0	5.8	1.7	7.0	1.0–7.0
3 My family really tries to help me.	259	82.6	5.8	1.8	7.0	1.0–7.0
4 I get the emotional help and support I need from my family.	259	81.5	5.7	1.8	7.0	1.0–7.0
5 I have a special person who is a real source of comfort to me.	260	85.0	5.9	1.6	7.0	1.0–7.0
6 My friends really try to help me.	259	64.5	5.0	1.9	5.0	1.0–7.0
7 I can count on my friends when things go wrong.	258	65.5	5.0	1.9	5.0	1.0–7.0
8 I can talk about my problems with my family.	256	80.1	5.7	1.8	7.0	1.0–7.0
9 I have friends with whom I can share my joys and sorrows.	257	63.4	5.0	2.0	5.0	1.0–7.0
10 There is a special person in my life who cares about my feelings.	261	81.2	5.8	1.7	7.0	1.0–7.0
11 My family is willing to help me make decision.	260	78.8	5.7	1.9	7.0	1.0–7.0
12 I can talk about my problems with my friends.	260	63.8	4.9	2.0	5.0	1.0–7.0
Global scale	243	–	5.5	1.4	6.0	1.0–7.0
Family subscale	251	–	5.7	1.7	6.5	1.0–7.0
Friends subscale	254	–	4.9	1.8	5.2	1.0–7.0
Significant other subscale	255	–	5.8	1.4	6.3	1.0–7.0

TABLE 4 Subgroup differences in Multidimensional Scale of Perceived Social Support (MSPSS).

	MSPSS Global scale			MSPSS subscales								
				Family			Friends			Significant other		
	N	M	SD	N	M	SD	N	M	SD	N	M	SD
Age	0.412			0.189			0.350			0.878		
≤70 years	119	5.4	1.4	122	5.6	1.8	124	4.8	1.8	125	5.8	1.4
>70 years	122	5.5	1.4	127	5.9	1.7	128	5.0	1.8	128	5.8	1.4
Sex	0.821			0.941			0.452			0.966		
Male	134	5.5	1.4	137	5.7	1.7	139	4.9	1.7	137	5.8	1.4
Female	108	5.5	1.3	113	5.8	1.8	114	5.0	1.8	117	5.8	1.4
Educational level	0.245			0.785			0.026			0.834		
No university entrance	146	5.4	1.4	151	5.7	1.8	154	4.9	1.9	153	5.8	1.4
University entrance	66	5.7	1.2	68	5.8	1.7	68	5.4	1.4	69	5.9	1.3
Job	0.442			0.761			0.044			0.608		
Not working	207	5.4	1.4	214	5.7	1.7	217	4.9	1.9	216	5.8	1.4
Working	34	5.6	1.3	35	5.6	1.8	34	5.4	1.3	36	5.9	1.2
Family situation	<0.001			<0.001			0.016			<0.001		
Not in relationship	111	4.8	1.6	115	5.1	2.1	117	4.6	1.9	117	5.2	1.6
In relationship	131	5.9	1.0	135	6.3	1.0	136	5.2	1.6	137	6.3	0.9
Living situation	<0.001			<0.001			0.040			<0.001		
Alone	77	4.7	1.7	79	4.7	2.2	81	4.6	1.9	82	5.0	1.7
With others	165	5.8	1.1	171	6.2	1.1	172	5.1	1.7	171	6.2	1.0
Having children	0.033			0.004			0.720			0.069		
No	44	5.0	1.7	45	4.8	2.4	46	4.8	1.8	46	5.4	1.8
Yes	198	5.6	1.3	205	5.9	1.5	207	5.0	1.8	207	5.9	1.6

Note: Bold print figures: significant differences. No uni. entr.: Highest educational level is degree without university entrance; Univ. entr.: Highest educational level is degree with university entrance; N: number of patients; M: mean score; SD: standard deviation.

emotional support from wound care managers; they expressed thankfulness, confidence, trust and good conversations: 'I have a qualified nurse specialised in mobile wound care. She means a lot to me, she gives courage and confidence' (male, 85 years, DFU). Many acknowledged the professional experience of the wound care manager: 'My wound expert. She is very experienced, knowledgeable and trustworthy. I feel very well taken care of' (female, 84 years, other wound); 'Wound manager - Great confidence built - She still tells me a lot about prosthesis and phantom pain. I feel better after the consultation' (male, 79 years, DFU). Participants emphasized reliability and continuity in the care of the wound care manager: 'Wound manager is reliable - comes almost always at the same time' (male, 60 years, DFU). One participant even stated that the wound care manager was the only person he allows to care for the wound: 'I only let my wound manager see my wound, no one else' (female, 55 years, other wound). However, two participants mentioned no

relationship with the wound care manager or expressed dissatisfaction with the home nursing specialist and one participant lacked confidence in competencies of the wound care manager: 'I just need to be sure that wound care is done professionally. That the dressings don't fall apart after a few steps or cause pain after a while. That's why I've lost my trust in [Name of wound care service] a bit lately' (male, 59 years, other wound). One participant expressed dissatisfaction with being cared for by constantly changing staff. Besides the wound care manager, sometimes also the home nursing specialist or the general practitioner was involved in wound care. Some patients received wound care during dialysis and were thankful that this reduced the need for additional doctor's visits.

Considering discontinued/restricted activities, participants named sporting activities (e.g., swimming, going for a walk, hiking, cycling), household activities, mobility, personal hygiene, working, social activities, travelling

TABLE 5 Correlations between Multidimensional Scale of Perceived Social Support (MSPSS) and wound-specific, dermatology-specific and generic health-related quality of life.

	MSPSS subscales											
	MSPSS global scale			Family			Friends			Significant other		
	<i>r</i>	<i>p</i>	<i>N</i>	<i>r</i>	<i>p</i>	<i>N</i>	<i>r</i>	<i>p</i>	<i>N</i>	<i>r</i>	<i>p</i>	<i>N</i>
Wound-QoL-17												
Global	−0.030	0.639	241	−0.070	0.273	249	0.009	0.886	252	−0.072	0.254	252
Body	−0.065	0.313	242	−0.122	0.054	249	−0.004	0.947	252	−0.100	0.114	252
Psyche	−0.021	0.741	241	−0.040	0.527	248	−0.008	0.895	251	−0.033	0.604	252
Everyday life	0.027	0.674	240	−0.020	0.755	247	0.049	0.437	251	−0.030	0.641	250
DLQI												
Total score	−0.015	0.821	237	−0.114	0.074	245	0.071	0.264	248	−0.059	0.358	249
Symptoms	−0.114	0.078	239	−0.162	0.011	247	−0.028	0.664	250	−0.141	0.025	251
Daily activities	−0.011	0.870	233	−0.050	0.440	241	0.053	0.411	244	−0.061	0.339	245
Leisure	0.042	0.528	233	−0.046	0.480	241	0.092	0.152	243	0.008	0.901	245
Work/school	0.062	0.345	235	−0.091	0.156	243	0.145	0.023	246	0.028	0.659	247
Personal relationships	0.047	0.472	239	−0.007	0.915	247	0.061	0.336	250	−0.001	0.987	251
Treatment	−0.120	0.063	242	−0.160	0.011	250	−0.036	0.574	253	−0.122	0.052	254
EQ-5D-5L	0.172	0.008	237	0.162	0.011	244	0.153	0.016	247	0.136	0.032	248

Note: Bold print figures: significant correlations; N, number of patients; r, Spearman correlation coefficient; p, significance level.

as well as sexual activities: ‘I can’t work’ (male, 56 years, other wound); ‘We can’t go on holiday together with friends anymore’ (male, 60 years, DFU); ‘Swimming and sauna, as you cannot go into the water with the wounds’ (male, 79 years, leg ulcer); ‘Leisure activities impossible because of constant lying down and “sparing” of the foot and lower leg wounds on both sides for weeks’ (female, 84 years, other wound); ‘Can’t go to the toilet on my own, that’s my main problem – that concerns me’ (male, 76 years, DFU); ‘I can’t go shopping anymore’ (male, 60 years, DFU); ‘Impairment with partner in sexual area’ (male, 65 years, DFU). When asked for newly started activities, participants mostly mentioned sedentary activities in the domestic setting (e.g., reading, playing games, eating, painting, TV and radio) but also moderate sporting activities (e.g., short walks, home exercise and physiotherapy). Some mentioned wound care as new activity. Ten participants did not report any newly started activity.

Throughout the free-text survey, participants reported limiting circumstances, which impact on their social life. These included mental burden (e.g., fear of pain, fear of COVID-19, need for peace and quiet, quality of wound care affecting their mood), physical restrictions due to the wound or other diseases, disturbing medical products and impairing side-effects, stigmatization, and changes in life circumstances (i.e., imminent move

to nursing home): ‘I can’t undress in public, my legs look unsightly because of the split skin’ (male, 56 years, other wound); ‘24 hours dependent on assistance, sitting possible with difficulty’ (male, 78 years, other wound); ‘Due to the fear of pain when walking or that the bandage will slip, I only go out of the house for what is necessary (doctor’s appointments, pharmacy, etc.)’ (male, 59 years, other wound).

According to their free-text statements, 15 patients were grouped as having good social support, 10 were grouped as having little or no social support and 21 were grouped as unchanged support or missing information (Table 7). Patients grouped as having good social support also reported higher social support across all MSPSS scales. This difference was significant for the *global* scale (6.03 vs. 4.33, $p = 0.039$) and the *family* subscale (6.50 vs. 4.45, $p = 0.042$), but not for the *friends* (5.13 vs. 3.64, $p = 0.082$) and *significant other* subscales (6.45 vs. 5.38, $p = 0.232$).

4 | DISCUSSION

This study investigated the social support of European patients with chronic wounds, its association with HRQoL as well as changes in the social participation of these patients.

TABLE 6 Multiple logistic regression for global scale and subscales of Multidimensional Scale of Perceived Social Support (MSPSS).

Model fit	MSPSS subscales							
	MSPSS global scale (<i>n</i> = 200)		Family (<i>n</i> = 206)		Friends (<i>n</i> = 208)		Sig. other (<i>n</i> = 208)	
	<i>R</i> ² = 0.175 RegB	<i>p</i> < 0.001 Sig	<i>R</i> ² = 0.256 RegB	<i>p</i> < 0.001 Sig	<i>R</i> ² = 0.044 RegB	<i>P</i> = 0.007 Sig	<i>R</i> ² = 0.170 RegB	<i>p</i> < 0.001 Sig
Age	–	–	–	–	–	–	–	–
Sex ^a	–	–	–	–	0.501	0.041	–	–
Education ^b	–	–	–	–	–	–	–	–
Working situation ^c	–	–	–	–	–	–	–	–
Family situation ^d	0.462	0.043	–	–	0.470	0.061	0.576	0.010
Living situation ^e	0.645	0.008	1.476	<0.001	–	–	0.650	0.006
Having children ^f	0.724	0.002	0.997	0.001	–	–	0.530	0.024
EQ-5D-5L	–	–	0.634	0.082	0.880	0.035	–	–
constant	4.244	<0.001	2.239	0.001	3.590	<0.001	4.638	<0.001

Note: – independent variable not included in final model; bold print figures: significant variables.

Abbreviations: MSPSS, Multidimensional Scale of Perceived Social Support; RegB, regression coefficient; Sig, level of significance.

^aReference: male.

^bReference: degree without university entrance.

^cReference: not working.

^dReference: not in a relationship.

^eReference: living alone.

^fReference: not having children.

TABLE 7 Patients' results on Multidimensional Scale of Perceived Social Support (MSPSS) grouped by qualitative responses.

	MSPSS subscales											
	MSPSS global scale			Family			Friends			Significant other		
	<i>N</i>	<i>M</i>	<i>SD</i>	<i>N</i>	<i>M</i>	<i>SD</i>	<i>N</i>	<i>M</i>	<i>SD</i>	<i>N</i>	<i>M</i>	<i>SD</i>
Support												
Good	14	6.0*	0.6	15	6.5*	0.6	15	5.1	1.2	15	6.5	0.5
Little to none	9	4.3*	1.9	10	4.5*	2.3	9	3.6	1.8	10	5.4	1.8
Unchanged/n.a.	18	5.3	1.4	20	5.4	1.9	20	5.1	1.5	20	5.4	1.8

Note: Mean differences between good support and few to no support were calculated using Mann–Whitney *U*-test; **p* < 0.05; n.a. not available.

Results revealed, on average, high social support according to the MSPSS questionnaire. It was slightly higher from family and a significant other than from friends. However, scores ranged across the whole span of the scale, implying that some patients did not receive sufficient support. Other international studies applying the MSPSS showed similarly high item and (sub-) scale scores in populations other than people with chronic wounds.^{27–29} A previous study using the MSPSS questionnaire in patients with diabetic foot ulcers¹¹ revealed considerably lower average scores than the present study or studies in other populations. Nevertheless, in that study, social support values also ranged across the whole span.

Some of our findings are in line with previous studies examining patients with chronic wounds. Similar to our study, they found associations of social support with the living situation^{27,30} but did not find significant associations with age or gender.³¹ In contrast to our study, associations of social support with marital status and formal education were not found in patients with diabetic foot ulcers.³¹ No previous study investigated the association between social support and having children in ulcer patients, which in our study was significant regarding global and family support.

This is, to our knowledge, the first study investigating the association of social support and wound-specific

HRQoL. Contrary to our research hypothesis, we did not find these two constructs to be associated. A possible explanation could be that the wording of the MSPSS is neither wound-specific nor disease-related and, hence, assesses generic social support. Therefore, respondents might not consider the disease- or wound-specific support they receive when completing the questionnaire. However, we did find associations between social support and other HRQoL perspectives. First, two dimensions of skin-specific HRQoL were related to social support: the more support from the family and a significant other, the less the symptom-related burden; the more support from a significant other, the less the treatment-related burden. Second, generic HRQoL was significantly, though weakly, correlated with social support from any source. This is comparable to previous studies in different chronic conditions, such as diabetes mellitus, Parkinson's disease, heart failure, chronic obstructive pulmonary disease and HIV.^{27,32} In contrast, one study on elderly people living alone found negative correlations between social support and physical HRQoL.²¹

As correlations do not allow for statements about causality, we can only make assumptions about the direction of causality between social support and HRQoL. Both directions are plausible: On the one hand, social support can, directly and indirectly, improve the patient's health³³ and, hence, HRQoL. Receiving social support can foster a sense of belonging in individuals, which in turn improves their health status.³⁴ Additionally, it can buffer stressful episodes.³³ This buffering effect has also been shown in a study in patients with chronic wounds, where social support mediated the relationship between ulcer pain and HRQoL.³⁵ Beyond its effect on the health status, higher perceived social support is associated with being better informed about the individual health status and self-care behaviours.³⁶ The association between social support and recurrence of wounds is still unknown; while one study found lower social support to be associated with recurrence,³⁷ another study did not find any difference in social support between patients with and without recurrent wounds.³⁸

On the other hand, the health status might affect social support of patients with chronic wounds.^{19,39} Experiencing pain and restricted mobility can cause impairments in everyday life activities, which is why patients with chronic wounds require increased tangible support. Additionally, feeling shame due to wound odour and exudate can lead to rejection or inability to socially participate,^{40–42} which increases the demand for emotional support. Resulting from this increased need for social support, being around a person with a chronic wound could stimulate to increase in the amount of support family and friends are willing to provide. Thereby,

the simultaneous increase of demand and supply might possibly result in a levelling of these effects, which could explain low levels of correlation between HRQoL and social support in our study.

The qualitative results in our study display a range of restricted activities, including activities of daily living. Restrictions in doing housekeeping, going shopping or personal hygiene imply the higher need for support from family members. Our participants also reported that family members provide daily wound care which was also found in previous studies.^{43–51} Even though support from family members is most highly valued by patients and even enables them to live their lives,^{45,52} it can also turn them into the role of a care-dependent and make them feel like a child.⁴⁷ In addition, this can impose a high burden and restrictions in the care provider's life.⁵³ Providing wound care requires knowledge and education. However, findings that almost no self-treating patients receive appropriate training,⁵⁴ it may be assumed that the same is true for informal caregivers. Appropriate education would be required to support family caregivers and ensure good wound care.

Despite the large number of patients with good social support, reports differed widely with some people reporting having only few contacts. In previous studies, some patients also reported to not receive the support they wished for either because they had no one to ask for it or because they did not want to bother their relatives.^{43,48,55,56}

Patients in our study highly valued the wound care received from professional caregivers as well as the emotional support they provided. Wound care managers and other nursing specialists have an important role beyond the mere provision of wound care. Patients in a previous study reported that receiving care from a professional could evade uncomfortable situations with close family members, for example when the carer is a sibling of similar age.⁴³ Professional wound carers were a source for trust and good conversations if continuous care by the same person(s) allowed this relationship to be developed. The contact with professional carers has previously been identified as an important source of social support,^{47,51} especially in long-lasting patient-carer relationships.⁵⁷

The major strength of this study is that to our knowledge, this is the first investigation of associations between patients' perceived social support and different types and dimensions of HRQoL. Recruiting of patients from centres in different countries prevented centre effects and enabled the inclusion of a broad range of patients. The use of both quantitative and qualitative methods allowed the comparison and integration of results from different approaches. Both quantitative and qualitative results display high levels of social support in the overall sample,

while showing large inter-individual differences. Additionally, the mixed-methods integration confirms that qualitatively identified levels of social support are reflected in the quantitative results, which supports the trustworthiness of both methods.

The international character of the study posed some methodological limitations. Value sets of the EQ-5D-5L were not available for all participating countries, which is why we used a single national value set for all countries. Regarding the MSPSS, a systematic review found limited evidence of generalizability across language versions.⁵⁸ Finally, for capacity reasons, the free-text survey could only be conducted in German-speaking countries. Another limitation is that we only included patients who are being treated in ambulatory clinics and, therefore, cannot make any statements about people with chronic in other settings.

This study revealed a relatively high level of perceived social support in patients with chronic wounds but with large variation between individual patients. This was supported by both quantitative and qualitative findings. To date, only few studies about family carers in patients with chronic wounds are available. Gaining further insights into their importance for the patient and their own impairments would allow to develop strategies to relieve burden. Additionally, increased consideration of this important stakeholder group in routine care could lead to better-educated non-professional carers and, hence, ensure high-quality wound care.

ACKNOWLEDGEMENTS

The authors thank the Scientific Communication Team of the IVDP, in particular Sara Tiedemann and Mario Gehoff, for copy editing. Open Access funding enabled and organized by Projekt DEAL.

FUNDING INFORMATION

This study was partially funded by the European Academy for Dermatology and Venereology (EADV).

CONFLICT OF INTEREST STATEMENT

Toni Maria Janke: none; Vlastimil Kozon: none; Skaidra Valiukeviciene: none; Laura Rackauskaite: none; Adam Reich: has been a consultant or speaker for AbbVie, Bioderma, Boehringer Ingelheim, Celgene, Chema Elektromet, Eli Lilly, Galderma, Janssen, Leo Pharma, Medac, Menlo Therapeutics, Novartis, Pierre-Fabre, Sandoz and Trevi Therapeutics; and principal investigator or sub-investigator in clinical trials sponsored by Abbvie, Alvotech, Amgen, AnaptysBio, Argenx, Biothera, BMS, Celgene, Celltrion, Dermira, Galderma, Inflarx, Janssen, Kiniksa, Kymab, Leo Pharma, Novartis, Pfizer, Trevi Therapeutics, UCB. KS: participated in clinical trials as

sub-investigator sponsored by Amgen, Anaptys, Almirall, Celltrion, Galderma, Kiniksa, Novartis, Trevi Therapeutics and was an invited speaker by Medac and Novartis; PC: none; MJ: none; CVM: none; SA: none; MB: none; ECM: none; MA: has received fees for consulting and/or lectures and/or studies from the following companies: 3M Medica, AOK Bundesverband, Bayer Healthcare, Beiersdorf, Birken, Bode, B. Braun, BSNmedical/Essity, BVmed, Coloplast, DAK, Diabet concept, Gerromed, GlaxoSmithKline, Johnson & Johnson, Lohmann & Rauscher, medi, Medovent, Mölnlycke, Smith & Nephew, Schülke & Mayr, Sörling, Sorbion, Systagenix, Uluru, Urgo; CB is project lead of the HAQOL study, which has been partly funded by the EADV; project proposal has been submitted by MA.

DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available from the corresponding author upon reasonable request.

ORCID

Toni Maria Janke  <https://orcid.org/0000-0002-9861-9519>

Matthias Augustin  <https://orcid.org/0000-0002-4026-8728>

REFERENCES

- Dissemond J, Bültemann A, Gerber V, Jäger B, Münter C, Kröger K. Definitionen für die Wundbehandlung. *Hautarzt*. 2016;67(3):265-266.
- Martinengo L, Olsson M, Bajpai R, et al. Prevalence of chronic wounds in the general population: systematic review and meta-analysis of observational studies. *Ann Epidemiol*. 2019;29:8-15.
- Olsson M, Järbrink K, Divakar U, et al. The humanistic and economic burden of chronic wounds: a systematic review. *Wound Repair Regen*. 2019;27(1):114-125.
- Edwards H, Finlayson K, Skerman H, et al. Identification of symptom clusters in patients with chronic venous leg ulcers. *J Pain Symptom Manag*. 2014;47(5):867-875.
- Neil J, Munjas B. Living with a chronic wound: the voices of sufferers. *Ostomy Wound Manag*. 2000;46(5):28-38.
- Blome C, Baade K, Debus ES, Price P, Augustin M. The "Wound-QoL": a short questionnaire measuring quality of life in patients with chronic wounds based on three established disease-specific instruments. *Wound Repair Regen*. 2014;22(4):504-514.
- Bullinger M. Das Konzept der Lebensqualität in der Medizin-Entwicklung und heutiger Stellenwert. *Z Evid Fortbild Qual Gesundheitswes*. 2014;108(2-3):97-103.
- Greenhalgh J, Gooding K, Gibbons E, et al. How do patient reported outcome measures (PROMs) support clinician-patient communication and patient care? A realist synthesis. *J Patient Rep Outcomes*. 2018;2:42.
- U.S. Food and Drug Administration. Guidance for industry. Patient-Reported Outcome Measures: Use in Medical Product

- Development to Support Labeling Claims 2009 [cited 2022 Nov 18]. Available from: URL <https://www.fda.gov/media/77832/download>
10. Bosanquet DC, Harding KG. Wound duration and healing rates: cause or effect? *Wound Repair Regen.* 2014;22(2):143-150.
 11. Yildiz E, Asti T. Determine the relationship between perceived social support and depression level of patients with diabetic foot. *J Diabetes Metab Disord.* 2015;14:59.
 12. Franks PJ, Moffatt CJ. Do clinical and social factors predict quality of life in leg ulceration? *Int J Low Extrem Wounds.* 2006;5(4):236-243.
 13. Douglas H, Georgiou A, Westbrook J. Social participation as an indicator of successful aging: an overview of concepts and their associations with health. *Aust Health Rev.* 2017;41(4):455-462.
 14. Langford CP, Bowsher J, Maloney JP, Lillis PP. Social support: a conceptual analysis. *J Adv Nurs.* 1997;25(1):95-100.
 15. Klein TM, Andrees V, Kirsten N, Protz K, Augustin M, Blome C. Social participation of people with chronic wounds: a systematic review. *Int Wound J.* 2021;18(3):287-311.
 16. Gorecki C, Brown JM, Nelson EA, et al. Impact of pressure ulcers on quality of life in older patients: a systematic review. *J Am Geriatr Soc.* 2009;57(7):1175-1183.
 17. Herber OR, Schnepf W, Rieger MA. A systematic review on the impact of leg ulceration on patients' quality of life. *Health Qual Life Outcomes.* 2007;5(44):1-12.
 18. Wise G. The social ulcer. *Nurs Times.* 1986;82(21):47-49.
 19. Brown A. Does social support impact on venous ulcer healing or recurrence? *Br J Community Nurs.* 2008;13(3):S6-S15.
 20. Moffatt CJ, Franks PJ, Doherty DC, Smithdale R, Steptoe A. Psychological factors in leg ulceration: a case-control study. *Br J Dermatol.* 2009;161(4):750-756.
 21. Kim J, Lee J-E. Social support and health-related quality of life among elderly individuals living alone in South Korea: a cross-sectional study. *J Nurs Res.* 2018;26(5):316-323.
 22. Zimet GD, Powell Suzanne S, Farley GK, Werkamn S, Berkoff KA. Psychometric characteristics of the multidimensional scale of perceived social support. *J Pers Assess.* 1990; 55(3&4):610-617.
 23. Finlay AY, Khan GK. Dermatology Life Quality Index (DLQI)—a simple practical measure for routine clinical use. *Clin Exp Dermatol.* 1994;19(3):210-216.
 24. Herdman M, Gudex C, Lloyd A, et al. Development and preliminary testing of the new five-level version of EQ-5D (EQ-5D-5L). *Qual Life Res.* 2011;20(10):1727-1736.
 25. Ramos-Goñi JM, Craig BM, Oppe M, et al. Handling data quality issues to estimate the Spanish EQ-5D-5L value set using a hybrid interval regression approach. *Value Health.* 2018;21(5): 596-604.
 26. Mayring P. *Qualitative Inhaltsanalyse: Grundlagen und Techniken. 11. Neuauflage.* Beltz; 2010 (Beltz Pädagogik). Available from: URL: <http://nbn-resolving.org/urn:nbn:de:bsz:31-epflicht-1143991>
 27. de Maria M, Vellone E, Durante A, Biagioli V, Matarese M. Psychometric evaluation of the multidimensional scale of perceived social support (MSPSS) in people with chronic diseases. *Ann Ist Super Sanita.* 2018;54(4):308-315.
 28. López Ramos Y, Fernández Muñoz JJ, Navarro-Pardo E, Murphy M. Confirmatory factor analysis for the multidimensional scale of perceived social support in a sample of early retirees enrolled in university programs. *Clin Gerontol.* 2017; 40(4):241-248.
 29. Osman A, Lamis DA, Freedenthal S, Gutierrez PM, McNaughton-Cassill M. The multidimensional scale of perceived social support: analyses of internal reliability, measurement invariance, and correlates across gender. *J Pers Assess.* 2014;96(1):103-112.
 30. Morgan PA, Franks PJ, Moffatt CJ, et al. Illness behavior and social support in patients with chronic venous ulcers. *Ostomy Wound Manage.* 2004;50(1):25-32.
 31. Figueira AL, Boas LC, Freitas MC, Foss MC, Pace AE. Perception of social support by individuals with diabetes mellitus and foot ulcers. *Acta Paulista De Enfermagem.* 2012;25:20-26.
 32. Mendonca CJ, Newton-John TRO, Alperstein DM, Begley K, Hennessy RM, Bulsara SM. Quality of life of people living with HIV in Australia: the role of stigma, social disconnection and mental health. *AIDS Behav.* 2023;27(2):545-557.
 33. Cohen S, Wills TA. Stress, social support, and the buffering hypothesis. *Psychol Bull.* 1985;98(98):310-357.
 34. Berkman LF. The role of social relations in health promotion. *Psychosom Med.* 1995;57:245-254.
 35. Ren H, Wan D, Ding Y, et al. Does social support moderate wound pain and health-related quality of life in patients with chronic wounds? *J Wound Ostomy Continence Nurs.* 2021;48(4):300-305.
 36. Laopoulou F, Kelesi M, Fasoi G, Vasilopoulos G, Polikandrioti M. Perceived social support in individuals with diabetic foot ulcers: a cross-sectional survey. *J Wound Ostomy Continence Nurs.* 2020;47(1):65-71.
 37. Finlayson KJ, Parker CN, Miller C, Edwards HE, Campbell J. Decreased mobility, lack of social support, haemosiderosis and use of antidepressant medications may predict recurrent venous leg ulcers within 12 months of healing: a prospective longitudinal study. *Phlebology.* 2022;37(3):206-215.
 38. Probst S, Bobbink P, Séchaud L, Buehrer SM. Venous leg ulcer recurrences—the relationship to self-efficacy, social support and quality of life—a mixed method study. *J Adv Nurs.* 2021;77(1): 367-375.
 39. Levasseur M, Desrosiers J, Tribble DS-C. Comparing the disability creation process and international classification of functioning, disability and health models. *Can J Occup Ther.* 2007; 74:233-242.
 40. Sehlo MG, Alzahrani OH, Alzahrani HA. Illness invalidation from spouse and family is associated with depression in diabetic patients with first superficial diabetic foot ulcers. *Int J Psychiatry Med.* 2016;51(1):16-30.
 41. Jackson DE, Durrant LA, Hutchinson M, Ballard CA, Neville S, Usher K. Living with multiple losses: insights from patients living with pressure injury. *Collegian.* 2018;25(4): 409-414.
 42. Lacerda FK, Carvalho ES, Araújo EM, Miranda NB, Dias AL, Almeida TA. Women with sickle anemia living with leg ulcers and pain. *Rev Enfermagem UFPE.* 2014;8(7):2054-2060.
 43. Adni T, Martin K, Mudge E. The psychosocial impact of chronic wounds on patients with severe epidermolysis bullosa. *J Wound Care.* 2012;21(11):528-530-6, 538.
 44. Bandeira LA, dos Santos MC, Duarte ÊRM, Bandeira AG, Riquinho DL, Vieira LB. Social networks of patients with chronic skin lesions: nursing care. *Rev Bras Enferm.* 2018;71: 652-659.

45. Garcia AB, Müller PV, Paz PO, Duarte ÊRM, Kaiser DE. Perception of users on self-care of lower leg ulcers. *Rev Gaucha Enferm.* 2018;39(1):1-19.
46. da Silva DC, Budó ML, Schimith MD, Ecco L, Costa IKF, Torres GV. Experiences constructed in the process of living with a venous ulcer. *Cogitare Enferm.* 2015;20(1):13-19.
47. da Silva DC, Budó MD, Schimith MD, et al. Influence of social networks on the therapeutic itineraries of people with venous ulcer. *Rev Gaucha Enferm.* 2014;35(3):90-96.
48. Fox C. Living with a pressure ulcer: a descriptive study of patients' experiences. *Br J Community Nurs.* 2002;7(6):10-14.
49. Perini C, Stauffer Y, Grunder M, Gandon M, Datwyler B, Hantikainen V. The meaning of caring from the viewpoint of patients with wounds due to peripheral vascular disease. *Pflege.* 2006;19(6):345-355.
50. Bradbury SE, Price P. Diabetic foot ulcer pain: the hidden burden (part two). *EWMA J.* 2011;11(2):25-37.
51. Byrne O, Kelly M. Living with a chronic leg ulcer. *J Community Nurs.* 2010;24(5):46-54.
52. Hopkins A, Dealey C, Bale S, Defloor T, Worboys F. Patient stories of living with a pressure ulcer. *J Adv Nurs.* 2006;56(4):345-353.
53. Adelman RD, Tmanova LL, Delgado D, Dion S, Lachs MS. Caregiver burden: a clinical review. *JAMA.* 2014;311(10):1052-1060.
54. Kapp S, Santamaria N. How and why patients self-treat chronic wounds. *Int Wound J.* 2017;14(6):1269-1275.
55. Palaya J, Pearson S, Nash T. Perception of social support in individuals living with a diabetic foot: a qualitative study. *Diabetes Res Clin Pract.* 2018;146:267-277.
56. Brod M. Quality of life issues in patients with diabetes and lower extremity ulcers: patients and care givers. *Qual Life Res.* 1998;7(4):365-372.
57. Hopkins A. Disrupted lives: investigating coping strategies for non-healing leg ulcers. *Br J Nurs.* 2004;13(9):556-563.
58. Dambi JM, Corten L, Chiwaridzo M, Jack H, Mlambo T, Jelsma J. A systematic review of the psychometric properties of the cross-cultural translations and adaptations of the Multidimensional Perceived Social Support Scale (MSPSS). *Health Qual Life Outcomes.* 2018;16(1):80.

How to cite this article: Janke TM, Kozon V, Barysch M, et al. How does a chronic wound change a patient's social life? A European survey on social support and social participation. *Int Wound J.* 2023;1-13. doi:[10.1111/iwj.14309](https://doi.org/10.1111/iwj.14309)