

Social participation of people with chronic wounds: A systematic review

Toni Maria Klein 몓	
Matthias Augustin 💿	

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

Correspondence

Toni Maria Klein, M.Sc., German Center for Health Services Research in Dermatology (CVderm), Institute for Health Services Research in Dermatology and Nursing (IVDP), University Medical Center Hamburg-Eppendorf (UKE), Martinistraße 52, 20246 Hamburg, Germany. Email: t.klein@uke.de

Christine Blome

Valerie Andrees | Natalia Kirsten | Kerstin Protz |

Abstract

Living with chronic ulcers can be burdensome and restrictive, with regard to not only physical and psychological but also social well-being. This review aims to analyse social participation in patients with chronic wounds and to compare results across different wound types. A search string was applied in several electronic databases. Results were screened according to predefined inclusion and exclusion criteria. Data of eligible articles were extracted and synthesised narratively. The search revealed 42 eligible publications. Only minor differences across different ulcer types could be detected. Overall, family members were the main social contacts for patients; they often provided wound care and emotional support. Patients had few non-family relations, but those existing were often very close. Patients felt guilty as their condition imposed burden on family and friends, as well. A close relationship with nurses was described. Restrictions were caused by direct and indirect consequences of the wound. Overall, social support and social connections were reduced in wound patients. Inconsistent results were found regarding social isolation. In summary, people with chronic wounds experience impairments in all aspects of social participation. Therefore, social participation deserves increased attention in routine care both as a trigger of burden and as an outcome of therapy.

KEYWORDS

social isolation, social participation, social support, ulcer, wounds and injuries

1 INTRODUCTION

Living with chronic wounds can be burdensome and can cause various restrictions in patients' daily life. A wound becomes chronic when it fails to show sufficient healing in a timely manner.¹ The exact timeframe after which a wound is considered chronic ranges from 4 weeks to

3 months.^{2,3} Besides the duration of the wound, the existence of an underlying condition is an indicator to define a wound as chronic.⁴ Chronic wounds can have different underlying aetiologies, such as venous insufficiency, arterial disease, diabetes, or constant pressure.⁵ Worldwide, the pooled total prevalence of chronic wounds is 1.67 per 1,000 people⁶ with especially high

This is an open access article under the terms of the Creative Commons Attribution-NonCommercial License, which permits use, distribution and reproduction in any medium, provided the original work is properly cited and is not used for commercial purposes.

© 2020 The Authors. International Wound Journal published by Medicalhelplines.com Inc (3M) and John Wiley & Sons Ltd.

└WILEY_ [WJ

prevalence in older adults.⁷ Age also negatively effects healing and recurrence as well as treatment adherence.^{8,9} People with chronic wounds often have reduced health-related quality of life (HRQoL) with regard to various dimensions.¹⁰⁻¹² Patients may not only experience wound-specific burden, such as exudate, odour, and pain but also more general impairments, such as depressions, anxiety, and sleep disturbances.^{13,14} Furthermore, many people with chronic wounds are financially burdened and restricted in their activities,¹⁵ all of which can result in impairments in patients' social participation.

Social participation and its impact on health have been described by Douglas et al.¹⁶ They define different forms of social participation:

- Social connections: ties with people in the individual's intimate or extended environment.
- Informal social participation: activities with others being pursued by the individual for own enjoyment by taking advantage of social interaction.
- Volunteering: activities in organisations (eg, community, church) being pursued by the individual for others' benefit.

They suggested that the positive effects of these forms of social participation on the individual's health are mediated by:

- Social support: help and assistance for the individual when it is needed.
- Social cohesion: the individual's sense of trust and reciprocity in the community.

This model is used for this review because of its distinct and clear definition of different aspects of social participation. Other authors may use different names for the same aspects of social support.¹⁷⁻²¹ Another reason for using this model is the fact that it was established in the context of older adults, which is an important target group with regard to chronic wounds.

Social participation can be beneficial in two ways: by buffering specific stressors in stressful episodes or by having a constant beneficial impact on health irrespectively of the presence of stressors.²² According to Berkman,²³ social support can improve health by enabling the individual to experience a sense of belonging and intimacy. However, negative consequences of social support might occur for both providers of support and patients. From the provider's perspective, providing informal care can be burdensome and cause adverse health outcomes.²⁴ From the patient's perspective, extensive support can foster patients' dependency.²⁵ Especially in the absence of family and friends, patients may become dependent from

Key Messages

- Chronic wounds pose major restrictions upon patients, not only regarding physical and mental health but also social life. To date, no study has compared social participation across various wound types.
- The aim of this article was to review literature about social participation of people with chronic wounds and to compare results across different wound types.
- Only minor differences between results of studies investigating different wound types could be detected.
- Family is consistently described as the major source of social support and social participation; mostly, a low number of relationships with friends are reported but those existing are described as very close. Patients with a continuous nurse relationship often report a unique relationship with this healthcare provider.

formal care providers. Therefore, it has been suggested that people with chronic wounds may hinder their wounds from healing or induce recurrence of wounds in order to preserve the contact to their nurses. This secondary gain of illness is called *social ulcer*.²⁶ This phenomenon is of rather anecdotal evidence²⁷ though secondary benefits from illness may occur. Beyond that, social participation not only influences health, but the health status also influences social participation.^{27,28} Accordingly, experiencing pain, having limited mobility, or feeling shame because of wound odour and wound exudate leads to patients' rejection or inability to socially participate.²⁹⁻³²

The issue of social participation requires special attention in people with chronic wounds. This is because people of higher age have more chronic wounds and less wound closure,^{7,8,33} and also the highest risk for reduced social participation up to social isolation.³⁴

Previous reviews have covered aspects of social participation in people with chronic wounds. However, they consider only specific dimensions of, or aspects related to, social participation, such as social impacts,³⁵⁻³⁷ psychosocial effects,³⁸ experiences of living with a chronic ulcer,³⁹⁻⁴¹ or patient-centred care.⁴² Social participation as described in the model presented earlier¹⁶ is a complex construct having great impact on the patients' well-being and should thus be considered accordingly in order to achieve a comprehensive understanding of the impacts of

288

chronic wounds on patients' life. Additionally, the previous reviews focused on one specific type of chronic wounds each, mostly leg ulcers^{36,38,39} and venous leg ulcers,^{27,37,40,41} or did not distinguish between different types of chronic wounds.⁴² Accordingly, no conclusion can be drawn whether social participation differs regarding the underlying aetiology. Although some consequences of chronic wounds are similar across wound types (eg, frequent wound dressings, restrictions in choice of clothes⁴²), others differ with regard to the underlying aetiology (eg, pain severity⁴³). Revealing potential differences in social participation in these patients could inform future research and clinical decision-making.

Therefore, the present review aims to describe the state of research on social participation in patients with chronic wounds, taking the different dimensions of social participation into account, and to compare results across different wound types.

2 | MATERIALS AND METHODS

The conduct of this systematic review has been registered at PROSPERO (CRD42020157433). We searched the electronic literature databases MEDLINE (PubMed), Cochrane Library, Web of Science, PsychINFO, and CIN-AHL. The search string combined keywords related to *chronic wounds* and *social participation*. Keywords on *chronic wounds* were based on search strings used by other systematic reviews on this indication^{42,44-46} and were discussed with a dermatologist (NK). Keywords on *social participation* were based on concepts covered in the model of social participation¹⁶ and systematic reviews about aspects of social participation.^{42,47-49} In collaboration with a librarian, the search string was finalised to be applicable in various databases. The search string as used in MEDLINE (PubMed) is displayed in Appendix 1.

All search results were extracted, and duplicates were removed. The titles and abstracts of the remaining records were screened by two researchers (TMK and VA) applying predefined exclusion criteria. Full texts were then assessed accordingly. Exclusion criteria were (a) studying nondermatological ulcers, (b) studying acute ulcers, (c) studying tropical ulcers, (d) social participation not being a major outcome of the study, (e) specific article types (ie, study protocols, case studies, no data collection), and (f) article language being neither English nor German. Literature reviews were not included, but articles cited by the reviews were screened related to title and reported content. In a last step, reference lists of eligible articles were screened for further relevant articles.

After identification of all eligible articles, data were extracted including information on the article, the study,

sample characteristics, wound type, and the perspective on and results regarding social participation. Wound types were stratified by articles reporting on patients with any form of leg ulcers (LU), venous leg ulcers (VLU), arterial leg ulcers (ALU), mixed leg ulcers (MLU), diabetic foot ulcers (DFU), pressure ulcers (PU), ulcers caused by other diseases, mixed samples of different types, and unspecified ulcer types. The perspective on social participation was categorised by articles treating social participation as a distinct construct, as a subdomain of HRQoL, or as aspect of another construct. Even though articles used different terminologies for the aspects of social participation covered here, their results were assigned to categories as defined by the model of Douglas et al,¹⁶ namely social support, social connections, informal social participation, volunteering, and social cohesion. At a later stage, informal social participation and volunteering were combined to informal/formal social participation because volunteering was seldom reported and, if so, only jointly with activities of informal social participation. Due to the heterogeneity of included studies, the large number of qualitative articles, and the variety of instruments used for assessing aspects of social participation, data were synthesised narratively.

The quality of all included studies was evaluated by applying checklists of the Critical Appraisal Skills Programme (CASP). These checklists exist for a variety of study designs. As no CASP checklist exists for cross-sectional studies, the CASP checklist for case-control studies was adapted by excluding criteria about the control group (CASP criteria 4 and 6a). Studies with a mixed methods design were assessed using the CASP checklist for the corresponding quantitative design. The number of criteria in each CASP checklist ranged from 10 (qualitative, cross-sectional) to 13 (cohort). The evaluation for most criteria was threestepped (yes/can't tell/no), except for criterion 9 in crosssectional studies ("Do you believe the results?": yes/no).

3 | RESULTS

Literature research in electronic databases identified 4,747 articles after removal of duplicates. After title and abstract screening, 96 articles remained. Full-text assessment identified 43 relevant articles, of which 32 were original studies and 11 were reviews. Reference screening was conducted accordingly. This process resulted in 42 eligible articles in total (Figure 1).

3.1 | Characteristics of included studies

The 42 articles included in this review present results of 40 studies and were published between 1986 and 2019



(Table 1). Of these, 24 were qualitative studies.^{25,30-32,50-69} Of the quantitative studies, 13 were cross-sectional⁷⁰⁻⁸² (of which six had a comparative approach, eg, ulcer vs nonulcer participants) and two were cohort studies.^{83,84} Three studies had a mixed-methods design.^{26,85,86} The number of patients with chronic wounds included ranged from 3⁶⁵ to 758.^{80,81} About half of the articles (n = 20) reported about studies conducted exclusively in the United Kingdom^{26,30,50,51,53,56,57,59,62,64,65,69,75,76,80,81,83-86} and seven articles about studies conducted in Brazil.^{25,31,52-55,58,61,64,65,70,71,77,79} The other articles reported studies from different countries. Results included 12 articles (21.8%) on patients with VLU,^{25,50,54,55,59,62,63,66,69,76,82,86} 9 articles (16.4%) on patients with LU, 26,60,72-75,78,80,81 8 articles (14.5%) on patients with DFU.^{53,61,64,65,70,71,77,79} 4 articles (7.3%) on patients with PU,^{30,57,67,68} and 3 articles (5.5%) on patients with ulcers caused by other diseases: rheumatoid arthritis,56 epidermolysis bullosa,⁵¹ and sickle anaemia.³¹ Four articles (7.3%) investigated patients with different wound types, 52,58,84,85 and one article (1.8%) did not specify the wound types.³² Most articles report on studies recruiting in an outpatient clinic or by district nurses; seven studies did not specify the setting of recruitment.53,65,67,69,72,74,77,79 One study each recruited patients exclusively in an inpatient clinic,⁷³ in both inpatient and outpatient clinics,³² or in a Leg Club.⁸⁵ Leg Clubs have been developed in the United Kingdom and are meetings in which community-based care is provided in nonmedical settings. Here, patients can drop in without appointment for being treated by a nurse and socialise

with other patients.⁸⁷ Leg Clubs have also been founded in Australia and Germany.88

In 16 articles, aspects of social participation were treated as distinct constructs, 25,26,50,52,58,61,71,73-77,79,83-85 in 7 as subdomains of HRQoL, 53,56,62,65,80,81,86 and in 19 they were described in the scope of another construct, 30-32,51,54,55,57,59,60,63,64,66-70,72,78,82 such as lived experience or psychosocial adjustment. In quantitative studies, aspects of social support were measured with a number of different questionnaires (eg, UCLA Loneli-Scale,⁸⁹ Inventory of Socially ness Supportive Behaviour,⁹⁰ and Medical Outcomes Study Social Support Survey⁹¹).

3.2 Quality assessment

In using different CASP checklists for the quality assessment, we acknowledged the difference in study designs. The assessment revealed mixed quality of the included articles (Table A1). In particular, quantitative studies did not fulfil or only partly fulfilled some of the CASP criteria. The number of fulfilled criteria ranged from one to eight of 10 across the cross-sectional and from five to six of 13 across cohort studies. Most of the quantitative studies lacked generalisability due to small sample sizes or low quality of study design. Within the qualitative studies, many fulfilled the majority of the 10 criteria, whereas others lacked the fulfilment of numerous

nt		's of	tion										inues)
SP Instrume	I	PAIS-SR, Way Coping instrument	Map construct indicators	I	I	I		SSQ-SF	I	I	I	Social support network inventory	- (Cont
Perspective on SP	Aspect of lived experience	Aspect of psychosocial adjustment	Distinct construct	Subdomain of HRQoL	Subdomain of HRQoL	Distinct construct	Aspect of lived experience	Distinct construct	Aspect of lived experience	Aspect of lived experience	Aspect of daily life	Distinct construct	Subdomain of HRQoL
Ulcer types	Epidermolysis bullosa ulcer	DFU	VLU, ALU, MLU, PU, unspecified ulcer	DFU	DFU	VLU	VLU	VLU	VLU	VLU	VLU	DFU	Rheumatoid arthritis foot ulcer
Age (years)	x̃ = 39.3 ± 17.4, range: 24 to 67	DFU: $\bar{x} = 61.84$ ± 9.34 ; controls: $\bar{x} = 55.22 \pm 3.77$	x̄ = 56, range: 37 to 79	Range: 71 to 86	x̄ = 57, range: 39 to 83	n/a	n/a	x̄ = 72, range: 30 to 95	Range: 47 to 79	Range: 47 to 79	Range: 40 to 81	x̃ = 57, range: 34 to 85	x̄ = 69 ± 10, range: 45 to 88
Sample size (n)	6	200 (DFU: 100, controls: 100)	6	£	14	8	12	65	14	14	8	30	23
Study design	Qualitative: interpretative phenomenology	Quantitative: comparative cross-sectional	Qualitative: social network analysis	Qualitative: not specified	Qualitative: not specified	Qualitative: not specified	Qualitative: Heideggerian hermeneutic phenomenology	Quantitative: cohort	Qualitative: not specified	Qualitative: not specified	Qualitative: social phenomenology	Quantitative: cross-sectional	Qualitative: not specified
Country	United Kingdom	Turkey	Brazil	United Kingdom	United Kingdom	United Kingdom	Ireland	United Kingdom	Brazil	Brazil	Brazil	Brazil	United Kingdom
Year	2012	2008	2018	2011	1998	2005	2010	2010	2014	2015	2013	2012	2011
Authors	Adni et al ⁵¹	Akca et al ⁷⁰	Bandeira et al ⁵²	Bradbury and Price ⁶⁵	Brod ⁵³	Brown ⁵⁰	Byrne and Kelly ⁶⁶	Charles ⁸³	da Silva et al ²⁵	da Silva et al ⁵⁴	da Silva et al ⁵⁵	Figueira et al ⁷¹	Firth et al ⁵⁶

TABLE 1 Details on the articles included in this study

(Continued)
-
Щ
Г
р
◄
F

P Instrument	ICLA Loneliness Scale; Closeness of Relationship Scale; Satisfaction with Relationship Scale		HI	HP	1						SSB	JCLA Loneliness Scale
Perspective on SP S	Aspect of U psychosocial aspects	Aspect of <i>patients'</i> - experience	Subdomain of N HRQoL	Subdomain of N HRQoL	Distinct construct –	Subdomain of HRQoL	Aspect of lived – experience	Aspect of lived experience	Aspect of lived – experience	Aspect of lived – experience	Distinct construct IS	Distinct construct U
Ulcer types	Tr	PU	L L L	TU	VLU, DFU	VLU	VLU	PU	ΓΩ	PU	LU, DFU	ΓΩ
Age (years)	Majority >60	Range: 31 to 64	$\tilde{x} = 74.6$ (women: $\tilde{x} = 76.9 \pm 10.5$; men: $\tilde{x} = 70.5$ ± 12.8)	$\bar{x} = 74.6$	Range: 32 to 70	x̃ = 71.45 ± 12.76, range: 46 to 91	Median: 75, range: 47 to 78	n/a	Range: 70 to 93	Range: 31 to 92	LU: $\bar{x} = 70.4$, DFU: $\bar{x} = 63.6$	Cases: $\bar{x} = 62.29$ ± 13.41, range: 34
Sample size (n)	28 (LU: 14, controls: 14)	5	758	758	10	38	8	∞	13	12	30 (LU: 15, DFU:15)	204 (LU:102, controls:102)
Study design	Quantitative: comparative cross-sectional	Qualitative: phenomenology	Quantitative: cross-sectional	Quantitative: cross-sectional	Qualitative: not specified	Mixed methods: cross- sectional	Qualitative: hermeneutic phenomenology	Qualitative: Heideggerian phenomenology	Qualitative: not specified	Qualitative: not specified	Quantitative: cohort	Quantitative: comparative cross-sectional
Country	New Zealand	United Kingdom	United Kingdom	United Kingdom	Brazil	United Kingdom	United Kingdom	Belgium and United Kingdom	Australia	United Kingdom	United Kingdom	Greece
Year	1994	2002	1998	2006	2018	2005	2004	2006	1999	2018	1997	2016 (a)
Authors	Flett et al ⁷²	Fox ⁵⁷	Franks and Moffat ^{*80}	Franks and Moffat ^{*81}	Garcia et al ⁵⁸	Hareendran et al ⁸⁶	Hopkins ⁵⁹	Hopkins et al ⁶⁷	Hyde et al ⁶⁰	Jackson et al ³⁰	Keeling et al ⁸⁴	Kouris et $al^{\dagger 73}$

SP Instrument	UCLA Loneliness Scale (Version 3)	I	I	NHP; MOS-SSS; COPE	SSQ	I	I	1	I	PAIS-SR, Ways of Coping instrument	I	I	RAND Social Health Battery	(Continues)
Perspective on SP	Distinct construct	Aspect of lived experience	Aspect of lived experience	Distinct construct	Distinct construct	Aspect of lived experience	Distinct construct	Subdomain of HRQoL	Aspect of caring	Aspect of psychosocial adjustment	Aspect of lived experience	Aspect of lived experience	Distinct construct	
Ulcer types	ΓΩ	Sickle anaemia ulcer	PU	LU	VLU	Unspecified ulcer	DFU	VLU	NTN	VLU	NTN	DFU	DFU	
Age (years)	LU: $\bar{x} = 52.34$ ± 11.77 ; psoriasis: $\bar{x} = 48.23$ ± 11.47 ; controls: $\bar{x} = 51.56 \pm 11.31$	Range: 27 to 35	$\bar{x} = 35.75$, range: 27 to 52	59% >75	x̃ = 73.5, range: 63.5 to 81.3		Range: 48 to 74	Range: 27 to 79 (IVDU-history: 27 to 41, non-IVDU- history: 44 to 79)	$\bar{\mathbf{x}} = 77$, range: 69 to 86	x̄ = 44.6 ± 4.3, range: 37 to 54	x̄ = 77, range: 55 to 89	x̄ = 57.3, range: 45 to 66	$\bar{x} = 55.78 \pm 8.02$, range: 40 to 71	
Sample size (n)	240 (LU: 80, psoriasis: 80, controls: 80)	S	8	190 (LU: 95, controls: 95)	74	10	8	19 (IVDU- history:7, no IVDU-history: 12)	12	32	4	13	69	
Study design	Quantitative: comparative cross-sectional	Qualitative: not specified	Qualitative: phenomenology	Quantitative: comparative cross-sectional	Quantitative: cross-sectional	Qualitative: Heideggerian hermenutic phenomenology	Qualitative: hermeneutic phenomenology	Qualitative: framework analysis	Qualitative: not specified	Quantitative: cross-sectional	Qualitative: Heideggerian hermenutic phenomenology	Qualitative: constant comparison approach	Quantitative: cross-sectional	
Country	Greece	Brazil	United States	United Kingdom	United Kingdom	United States	Australia	United Kingdom	Germany	United States	United Kingdom	United Kingdom	Indonesia	
Year	2016 (b)	2014	2000	2009	2004	2000	2018	2007	2006	2000	2003	2005	2019	
Authors	Kouris et al ^{†74}	Lacerda et al ³¹	Langemo et al ⁶⁸	Moffat et al ⁷⁵	Morgan et al ⁷⁶	Neil and Munjas ³²	Palaya et al ⁶¹	Palfreyman et al ⁶²	Perini et al ⁶³	Pieper et al ⁸²	Rich and McLachian ⁶⁹	Searle et al ⁶⁴	Septiana and Gayatri ⁷⁷	

TABLE 1 (Continued)

\sim	
eç	
ntinu	
Ŭ	
-	
Щ	
ĽΕ	
BLE	
ABLE	

s Perspective on SP SP Instrument	. Distinct construct 5-point Likert ed scale single item on social isolation	Distinct construct Townsend's Scale	Aspect of life PGC MAI situation	Distinct construct MSPSS	
Ulcer type	VLU, DFU, unspecifi ulcer	ΓΩ	P	DFU	
Age (years)	x̄ = 75.34 ± 10.31, range: 50 to 94	Retirement age	Ulcer men: $\tilde{x} = 79$ \pm 7, ulcer women: $\tilde{x} = 80$ \pm 3, controls men: $\tilde{x} = 80$ \pm 6.5, controls women: $\tilde{x} = 80$ \pm 5.4	10.2%: 18 to 30; 81.3%: 31 to 50; 8.6%: >50	
Sample size (n)	49	10	144 (LU: 70 controls: 74)	128	
Study design	Mixed methods: cohort	Mixed methods: cross- sectional	Quantitative: comparative cross-sectional	Quantitative: cross-sectional	
Country	United Kingdom	United Kingdom	Sweden	Turkey	
Year	2015	1986	2002	2015	
Authors	Upton et al ⁸⁵	Wise ²⁶	Wissing et al ⁷⁸	Yildiz and Asti ⁷⁹	

Note: $*/^{\dagger}$, articles reporting the same study.

Abbreviations: x, mean; ALU, arterial leg ulcers; COPE, multidimensional measure of strategies used for coping; DFU, diabetic foot ulcers; HRQoL, health-related quality of life; ISSB, Inventory of Socially Supportive Social Support; NHP, Nottingham Health Profile; PAIS-SR, Psychosocial Adjustment to Illness Scale—Self-Report; PGC-MAI, Philadelphia Geriatric Center Multilevel Assessment Instrument; SSQ, Social Support Behaviour; IVDU, intra-venous drug user; LU, any leg ulcers; MLU, mixed leg ulcers; PU, pressure ulcers; MOS-SSS, Medical Outcomes Study Social Support Survey; MSPSS, Multidimensional Scale of Perceived Questionnaire; SSQ-SF, Social Support Questionnaire short form; UCLA, University of California, Los Angeles; VLU, venous leg ulcers.

294

TABLE 2	Information on social suppor	rt as reported by studies differentiated by ı	ulcer type		
Social suppo	rt (n = 20)				
Types Studies	Venous leg ulcer $n = 6^{25,54,63,66,76,83}$	Any leg ulcer $n = 1^{75}$	Diabetic foot ulcer $n = 6^{53,61,64,65,71,79}$	Pressure ulcer $n = 3^{57,67,68}$	Other disease- $n = 1^{51}$
General	 Number of social contacts 	п.а.	Verv different stories	n.a.	п.а.

1 ypes Studies	$v = 6^{25,54,63,66,76,83}$	$n = 1^{75}$	$\mathbf{n} = 6^{53,61,64,65,71,79}$	$n = 3^{57,67,68}$	$\mathbf{n} = 1^{51}$	$n = 3^{52,58,84}$
General aspects	 Number of social contacts per item (esp. emotional support); 	n.a.	 Very different stories (family and friends as burden or lacking 	n.a.	n.a.	Some patients felt need to receive care but did not
	 Average: 1.4 Average: 1.4 Total range: 0-36 Mentioned contacts per item (esp. emotional support): family members, neighbours, nurses, GP, social workers, home help, God Overall high satisfaction with social support; average: 5.4 (score range: 0-6) Important to talk about problems Moments existing when patients do not want to talk in order not to burden another person 		 support versus vast number of strong relationships) Transport frequently mentioned as instrumental support Occasions described where financial support was needed Providing reciprocal support (sometimes wound/treatment restricts to provide support) Reluctant to talk about social support not they talked about general support not disease-specific Many internalise some of their thoughts 			 Patients felt Patients felt receiving 36% of possible support Most frequent received support; emotional support; least: guidance support support Social network doing wound care and providing psychological help
Informal providers	 Family (esp. those of closest relations, daughter, son, daughter-in-law, granddaughter): Doing first aid/wound care Consulted for decisions about provider/treatment Accompanying to physician Helping with housework (eg. laundry) Doing errands and excursions 	h.a.	 Family (esp. spouse/partner, daughter): Undertaking dressing Reminding to take analgesia Performing housework Patients express wish not to interfere children's life and burden themMain source of social support: 86.7% family 10.0% friends 	 Family (esp. spouse/partner, child): Undertaking dressings Anxiety of partner reported while doing dressings dressings Providing social interaction (highly appreciated by patients appreciated by patients Patients are aware of extra workload on family 	Family (esp. wife, family carer): (esp. wife, family carer as expert (knowing where it would hurt, how to dress/wash)	 Family (esp. family nucleus, wife): Doing wound care Washing/drying bandages Preparing food

(Continues)

excursionsEmotional support

Social suppor	rt(n=20)					
Types Studies	Venous leg ulcer n = 6 ^{25,54,63,66,76,83}	Any leg ulcer $n = 1^{75}$	Diabetic foot ulcer $n = 6^{53,61,64,65,71,79}$	Pressure ulcer $n = 3^{57,67,68}$	Other disease-caused ulcer n = 1 ⁵¹	Mixed sample n = 3 ^{52,58,84}
	 Support intensified over process of living with condition Expecting care from formerly cared for relative Exerting control/protecting and imposing rules/ treating patient like a child Patients doing all by themselves due to absence of family or not wanting to bother family Friends/neighbours: Emotional support Material support Service Help in searching provider Providing transport Colleagues: Fetching patient by car 		 6.7% church/ associations 3.3% boss/colleague 	 Patients note that life would have been worse without families Friends: Support and social interaction (highly appreciated by patients) 		
Formal providers	 Healthcare team provide major help Help intensifies over process of living with condition Relationship with healthcare team may be considered friendship/ kinship Unique relationship with nurse 	ħ.a.	Main source of social support: 26.7% health professionals 	u.a.	 Preferring formal carer to avoid awkward situations with family members 	Sh.a.

ocial sup lypes tudies	port (n = 20) Venous leg ulcer n = $6^{25;54,63,66,76,33}$	Any leg ulcer $n = 1^{75}$	Diabetic foot ulcer n = 6 ^{53,61,64,65,71,79}	Pressure ulcer $n = 3^{57,67,68}$	Other disease-caused ulcer n = 1 ⁵¹	Mixed sample n = 3 ^{52,58,84}
Froup different	Available support: ces	Total social support:	Perceived social support:	n.a.	n.a.	Received support:No statistical
	 Women more than men (<i>P</i> = .06) Women more than men at entry and exit of study (seen in all age groups) No sig. difference between younger (<70 years) and older patients (<i>P</i> = .16) Patients living with other people more than patients living alone (<i>P</i> = .042) Satisfaction with support: Women more than men (but <i>P</i> = .22) Younger (<70 years) more than older (>70 years) more than living alone than nen (but <i>P</i> = .22) Younger (<70 years) (<i>P</i> = .042) Living with other people more than living alone (<i>P</i> < .001) Healed patients more than non-healed patients at exit of study 	 Reduced in cases compared to controls (<i>P</i> = .008) Forms of social support: Reduced in cases compared to controls: positive interaction (<i>P</i> = .002); tangible (<i>P</i> = .017); emotional/informational (<i>P</i> = .028); affectionate (<i>P</i> = .055) Social coping strategies: More often used by controls than cases: seeking instrumental support (<i>P</i> < .001), seeking emotional support (<i>P</i> < .001), seeking emotional support (<i>P</i> < .001) 	 No sig. differences regarding age, formal education, gender, marital status, diagnosis, systolic/diastolic blood pressure, BMI, treatment Association with fasting plasma glucose (<i>P</i> = .02) Total, family, significant other support: Higher when shorter disease duration (0-10 years) compared to longer (>10 years) Total, family, friends, significant other support: All scales negatively correlated with Beck Depression Inventory 	20		difference between patients with leg ulcers and diabetic foot ulcers

Abbreviations: BMI, body mass index; GP, general practitioner; n, sample size; n.a., no information available.

TABLE 2 (Continued)

	ഉ	
	Ē	
	ulcer	
	20	,
	tea	
•	ntia	
	differe	
:	tudies	
	NO S	•
-	g	
	oort	
	Ē	
	sas	
	lon	
	ject	
	cont	
	cial	
	1 SO	
	0 u	
•	atio	
	r'n	
د ب	Into	
,	ر	
ļ	ц С	
ĥ	η	
	4	

D	ñ
ų	- 11
ti	<u> </u>
na	s
Ц	90
nfć	Ξ
П	ĕ
	- 10
ŝ	ō
Щ	1
H	ia
Ξ.	2
<	Š
H	

Social connect Type	ions (n = 25) Venous leg ulcer	Any leg ulcer	Diabetic foot ulcer	Pressure ulcer	Other disease-caused ulcer	Unspecified ulcer	Mixed sample
Studies	$n = 6^{50,55,59,62,69,82}$	$n = 9^{26,60,72-75,80,81}$	$n = 3^{70,71,77}$	$n = 3^{30,57,68}$	$n = 1^{31}$	$\mathbf{n} = \overline{1}^{32}$	$n = 2^{52,85}$
Frequency	 IVDU and non- IVDU report restrictions in interactions One fourth describe contact with significant other significant other close relationship with nurse close relationship with nurse One fourth admit feeling lonely 14% reporting lowest value in friends' interaction scale 	 Social contact score ranging from 12 to 52 For one women the nurse was the only contact 	 Social network consisting of three persons on average (ranging from 1 to 10) 87% of participants were classified as having poor social interaction 	n.a.	ћа.	 One patient staying in chat rooms (internet) for hours while being house bound 	 Characteristics of social network: small amplitude, few relationships, low density Social network composed entirely by relatives, sisters, children, wife
Experience	 Absence of close family network were not influencing feelings of isolation Contact with nurse being positive aspect of disease Feeling of being listened to resulting in attachment to nurse Varying levels of social connectedness Feeling socially disconnected: being inside, looking out Not able to join activities in 	 Looking forward to nurses, as they are the only contact Socially isolated old people making greater demands upon health and social services 	n.a.	 Varying severity of social isolation Staying in the room (even for meals); hospitalisation; bed rest One patient staying inside for eight months, admitting having no (social) life 	• Strong tendency to self-isolation	• Experiencing cabin fever	 51.1% of patients state that social situation improved through Leg Club Social isolation being relieved due to Leg Club Majority feels talked to in Leg Club compared to at a clinic

(Continued)
ŝ
щ
3L
F

Social connections (n = 25)

social conne	$(c_7 = u)$ suono				Other disease-caused		
Type Studies	Venous leg ulcer $n = 6^{50,55,59,62,69,82}$	Any leg ulcer $n = 9^{26,60,72-75,80,81}$	Diabetic foot ulcer $n = 3^{70,71,77}$	Pressure ulcer $n = 3^{30,57,68}$	ulter $n = 1^{31}$	Unspecified ulcer n = 1 ³²	Mixed sample n = 2 ^{52,85}
	 sheltered houses or to go downstairs Restrictions in sexuality and finding a partner Psychosocial adjustment impaired regarding vocational environment, social environment, extended family relationships, less regarding sexual relationships 						
Causes	 Ulcer major contributor to social isolation but also difficulties determining degree of social restrictions directly caused by leg ulcer Poor mobility (attributed to ulcer and bandages despite co- morbidities) Treatment regimens affecting ability to socialise (eg, inconvenience of dressings, time schedule) 	Age and chronicity of ulcer combined with physical limitations	n.a.	 Being bed-bound Restrictions caused by dressings 	 Odour Low self-esteem resulting from wound Pain Fear of reappearance 	 60% not able to get out Sitting in wheelchair due to ulcer Fear of infections Staying on specific mattress Immobility caused by wound Pain when walking 	n.a.

(Continues)

0
Ш
£
S
5
ţ
n,
-
ci 3
200

(Continued)
ŝ
ΓT]
Г
В
◄
F

N
- 11
<u>u</u>
tions
nect
cor
ial
Soc

Social conne	sctions $(n = 25)$				Other disease-caused	_		
Type Studies	Venous leg ulcer $n = 6^{50,55,59,62,69,82}$	Any leg ulcer $n = 9^{26,60,72-75,80,81}$	Diabetic foot ulcer $n = 3^{70,71,77}$	Pressure ulcer $n = 3^{30,57,68}$	ulcer n = 1 ³¹	Unspecified ulcer n = 1 ³²	Mixed sample n = 2 ^{52,85}	
		• No sig. difference between cases and	family relation $(P = .622)$					
		controls Ullcer natients 						
		similar to controls,						
		both less than						
		 psoriasis patients Cases more than 						
		controls $(P = .029)$						
		or age-/sex-matched						
		normal						
		scores ($P = .001$)						
		 For ulcer, psoriasis, controls: women 						
		more than men						
		Women more than						
		men ($P = .048$ /						
		P = .046); difference						
		from sex-matched						
		normal scores						
		higher in men than						
		in women (<i>P</i> < .001)						
		 Higher levels in 						
		older patients						
		(P = .044);						
		age-matched normal						
		scores higher in						
		younger age						
		groups ($P < .001$)						
		 Associated with size 						
		$>10 \text{cm}^2$ ($P = .032$)						
		and duration						
		>36 months						
		(P = .008)						
							(Continue	(Si



TABLE 3 (Continued)

criteria. The number of fulfilled criteria ranged from one to nine in qualitative studies. Most of the qualitative studies lacked a discussion of the relationship between researcher and participants.

3.3 | Social support

In 20 studies including patients with VLU,^{25,54,63,66,76,83} LU,⁷⁵ DFU,^{53,61,64,65,71,79} PU,^{57,67,68} other disease-caused ulcers,⁵¹ and different ulcer types,^{52,58,84} aspects of social support were reported (Table 2). Patients' experiences were similar across these ulcer types. Family members represented the main resource for social support, providing direct and indirect wound care as well as emotional support. Friends, neighbours, and colleagues most often provided emotional support, social interaction, and transport.^{31,51-55,57,58,63,65-68,71} Despite these overall positive impacts of family and friends, results varied across individuals and sometimes patients were not able to receive the support they wished for⁵² or patients deliberately avoided asking for help in order not to burden others.⁵³

3.4 | Social connections

In 25 studies, in which all ulcer types were represented, ^{26,30-32,50,52,55,59,60,62,68-75,77,78,80-82,85} aspects of social connections were reported (Table 3). No considerable differences between ulcer types were found. The number of people with whom patients had social connections varied within studies. Besides psychological aspects (eg, stress, worries) being negatively correlated with social connections, wound odour was the only clinical variable indicating fewer social connections.^{77,85} The number of social connections was also lower in comparison with healthy controls, ^{75,78} particularly regarding extra-family relations. Restrictions in sexuality and finding a partner were also reported.^{55,62,70}

Both direct consequences of chronic wounds (eg, being immobile, being bed-bound, sitting in a wheelchair, having pain when walking)^{30,32,50,57,60,68} and indirect consequences (eg, fearing that others could smell wound odour or see leakage)^{31,32,50,59}were associated with social isolation, which is an extreme manifestation of reduced social connections. However, results were inconsistent as to whether social isolation is significantly more frequent in patients with chronic wounds than in controls.^{72,74} One study found upward deviations from norm values across all patients, with larger deviations from the respective norm value in men and younger patients.⁸⁰

participation $(n = 17)$	a						
Type	Venous leg ulcer	Leg ulcer (unspecified)	Diabetic foot ulcer	Pressure ulcer	Other disease-caused ulcer	l Unspecified ulcer	Mixed sample
Studies	$\mathbf{n} = 7^{54,55,59,62,63,66,86}$	$n = 1^{78}$	$n = 2^{53,65}$	$n = 2^{30,67}$	$n = 2^{51,56}$	n = 1 ³²	$n = 2^{58,85}$
Restricted activities	 Work (work, university, retiring) Social activities (visiting family member, activities where bandage would be visible, remaining indoors) Leisure activities (fishing, dancing, part, playing football, running, walking) Travel (sightseeing, holiday away from home) 	 More common to give up activities for cases than for controls: voluntary work, outdoor activities, spectator activities (each <i>P</i> < .001), attending church (<i>P</i> < .01), playing cards (<i>P</i> < .05) 	 Leisure activities (hobbies, formerly enjoyed activities Travel (vacations) Everyday activities (household maintenance activities) 	 Leisure activities (preferred activities, exercising) 	 Work (ceasing work retirring, prolonged travel to work, problems managing active job) Social activities (cancelled plans/ trips with friends, social events, avoiding activities) Leisure activities (walking, dancing, gardening, badminton, shopping, swimming) Travel (affected holidays with walking/swimming) 	 Work Everyday activities (going to church and grocery store) 	 Leisure activities (sports) Everyday activities (tending pets)
Continued/ uptaken activities	 Partly very active social life reported 	n.a.	n.a.	n.a.	 Able to manage desk job 	na.	• Enjoying Leg Club and engaging in its structured activities
Causes	 Difficult/impossible to wear shoes or dress properly (Expected) inefficiency of treatment Pain Odour Lack of sleep Restricted mobility 	na.	 Less time/ stressful days due to increased time for foot care Restricted mobility 	 Shame and embarrassmen caused by odour Sense of not being able to enjoy 	 Unable to activities with weight bearing Necessity to keep ulcer dry Pain Reduced enjoyment Restriction in choice of shoe and 	na.	n.a.

TABLE 4 Information on (informal) social participation as reported by studies differentiated by ulcer type

(Informal) social

KLEIN ET AL.

303

IWJ_WILEY⊥

(Continued)	
4	
LΕ	
AB	
H	

ormal)	
(Inforn	

al	
·H.	
ŏ	
S	

-

participatio (n = 17)	ц						
Type	Venous leg ulcer	Leg ulcer (unspecified)	Diabetic foot ulcer	t Pressure ulcer	Other disease-cause ulcer	d Unspecified ulcer	Mixed sample
Studies	$n = 7^{54,55,59,62,63,66,86}$	n = 1 ⁷⁸	$n = 2^{53,65}$	$n = 2^{30,67}$	$n = 2^{51,56}$	$n = 1^{32}$	$n = 2^{58,85}$
	 Changes in personality traits (becoming introverted, low mood, depressive symptoms) Frequent dressings Discomfort due to/unattractiveness of bandage 				concerns of appearance		
Impact	 Financial issues (restricted work) Transforming to introverted closed life 	n.a.	 Shrinking of social circle Guilt about friends needing to change activities 	Become an inactive person	n.a.	n.a.	 Indigenous patient no longer accepted in community

Abbreviations: n, sample size; n.a., no information available.

TABLE 5 Information on social cohesion as reported by studies differentiated by ulcer type

Social cohesion (n = 11) Other disease-						
Type Studies	Venous leg ulcer n = $3^{59,63,86}$	Diabetic foot ulcer $n = 2^{53,65}$	Pressure ulcer n = 1 ⁶⁷	caused ulcer $n = 2^{31,51}$	Mixed sample $n = 3^{52,58,85}$	
Relationship with family and friends	 Good relationship with family members Many live together with spouse or in same house as child 	n.a.	n.a.	 Strong view on friendships and selected appropriate friends True friends perceived as having understanding and being non- judgmental 	 A stable bond with esp. family members can both help patient managing and inhibit self-care Fragility in affective bonds Partner of indigenous patient refused to sleep in same bed and partner's rejection of ulcer treatment leading to confrontations 	
Impact on family and friends	 Many felt family affected Some felt guilty leaving housework to partner on being dependent on them for self-care 	 Felt putting burden on family and impacting relationships Emotional tension and strain due to ulcer and diabetes transferred into relationship with family (esp. spouse) 	 Patient imagining that odour was most severe when other people are around Anxiety about family members and burden that ulcers puts on them and the worry it causes Restrictions of patient bring restrictions to others 	 g Sadness that pain bothers others Avoiding talking with family about pain, only with mother when pain is unbearable 	n.a.	
Relationship with formal carers	 Continuity in nurse leading to close relationship, sometimes describes as <i>mother-</i> <i>daughter relationship</i> or <i>close friendship</i> Patient with inconsistencies of care report no relationship with nurses at all (even not knowing name) 	n.a.	n.a.	n.a.	<i>n.a.</i>	

Abbreviations: n, sample size; n.a., no information available.

3.5 | Informal/formal social participation

Across all types of chronic wounds, 17 studies^{25,30,32,51,53,55,56,58,59,62,63,65-67,78,85,86} report restrictions with regard to work life, social activities, leisure activities, everyday activities, and travelling (Table 4). One study comparing ulcer patients and controls found significant differences in the frequency of activity cessation.⁷⁸ Causes for restrictions in activities were similar across ulcer types, such as immobility caused by the ulcer, inability to wear appropriate clothing, and restricted time due to increased effort put in wound care or appointments with formal care providers.^{30,53,54,56,58,59,62,63,67,86} Also, psychological impacts of the wound hindered patients to participate socially as patients were ashamed, were not able to enjoy formerly enjoyed activities, or behaved more introverted because of their ulcer.^{30,53,56,58,59,62,66,86} These restrictions could lead to financial problems, diminishing social networks or feelings of guilt because the patients' burden led to restrictions for others. Nevertheless, some patients reported to maintain their active social life or their desk jobs.^{56,59} The only reported newly uptaken activities were those offered by a Leg Club.⁸⁵

3.6 | Social cohesion

Eleven studies reported on social cohesion (Table 5) including patients with VLU,^{59,63,86} DFU,^{53,65} PU.⁶⁷ other disease-caused ulcers,^{31,51} and different ulcer types.^{52,58,85} In all ulcer types, patients reported feelings of guilt, anxiety, or sadness because of the burden that they felt was loaded onto family members or friends due to the patients' restrictions. Patients stated that their personal tension was transferred to the family, that they avoided talking to others about their issues, or that personal bonds became fragile.^{31,52,53,58,65,67,86}However, several studies also highlight patients' strong relationships with both family members and friends, which help managing self-care and having a safe environment with nonjudgemental people around.51,58,63 Moreover, VLU patients also describe a strong relationship with their nurses; however, this was only the case when there was consistency in the person providing care.⁵⁹

4 | DISCUSSION

The aim of this systematic review was to analyse social participation in patients with chronic wounds and to compare results across different ulcer types. For this, the model of the effect of social participation on health¹⁶ was used, and thus, results assigned to social support, social connections, informal/formal social participation, and social cohesion. Most of the included studies focused on social connections and social support. The most frequently studied patient groups were VLU patients, followed by patients with any LU (probably also including a large share of patients with VLU), DFU, and PU. This corresponds to the actual prevalence of wound types with most chronic wounds being chronic leg ulcers,⁶ and the greatest share of chronic wounds being venous aetiology.⁹²

This review reveals that no considerable differences have been found in the social participation of patients with different types of ulcers. Consistent results across the studies were that the main source of social contact was the family, who also provided wound care and relieved the patients from housework activities. Relationships with family members and friends were often close, but patients also feared to bother others. Patients often had to quit or rearrange previously conducted activities and only few reported newly uptaken activities. Accordingly, direct and indirect consequences of the chronic wound led to reduced social interactions and partly even caused social isolation. An inconsistent picture was seen regarding which sociodemographic, clinical, or psychological characteristics are associated with patients' social participation.

The importance of family members and spouses found in the included studies aligns with previous findings stating that family members and spouses are important caregivers and care coordinators for patients with various diseases (eg, stroke, musculosketeal diseases, depression).⁹³ In their role as caregivers, relatives can facilitate patient-centred care.⁹⁴ However, the great share of care provided by informal caregivers can also lead to high burden for relatives.⁹⁵ Therefore, it is important not to overlook this specific target group and to provide interventions to provide help, which has already shown positive effects for informal caregivers of patients with dementia and cancer.⁹⁶

The fact that only a small number of extrafamilial relationships was detected, but that those existing were often close and of non-judgemental nature, emphasises the importance to study not only the quantity of social contacts. Accordingly, Victor et al⁹⁷ reasoned that in the general population of older adults, the number of social contacts alone does not explain feelings of loneliness but that the individuals' experiences and understandings need to be investigated qualitatively. Despite the close relationships reported in the articles, some patients expressed a tendency to avoid bothering others. Together with direct consequences of the wound (eg, exudate, odour, pain, immobility, timeconsuming treatment), this may lead to restrictions in various activities as well as withdrawal from social interaction, and hence promote the risk of selfisolation and feelings of loneliness.

Besides family and friends, the unique relationship with professional healthcare providers (especially nurses) needs to be acknowledged. This relationship can go beyond the provision of wound care and become a resource of emotional support. For such a relationship to develop, it needs continuity in care and a collaborative relation between patient and provider. Additionally, continuity in and confidence with professional care may prevent patients from terminating professional care and from starting self-treatment. One third of self-treating wound patients were found to do so⁹⁸ (eg, for reasons of unavailability of the familiar care provider, differing ideas about the treatment across different care providers, inconvenience of professional care). Other reasons for self-treatment were the wish to be independent, the wish to conduct treatment at the desired time, or the costs caused by professional care. At the same time, this study⁹⁸ found that few patients were educated or trained for selftreatment, and that debridement was rarely conducted in self-performed wound care. This calls for a welldesigned educational programme for self-treating patients. The same accounts for informal caregivers, who often bear a large share of the wound care, but may still lack important knowledge and skills required for providing safe care.⁹⁹ On the contrary, a close relation to the nurse may also lead to the phenomenon of social ulcers.²⁶ This describes the patient's wish of the wound not to heal in order to maintain the social contact with the care provider and is probably particularly relevant for the patients with the lowest number of social contacts.

The major strength of this review is that, to our knowledge, it is the first study comparing social participation of patients across different types of chronic wounds. Based on the current state of research, no differences between types of chronic wounds could be detected regarding any aspect of social participation. Nevertheless, some limitations should be considered. To make results comparable, we assigned the content of each article to dimensions as used in the model of Douglas et al,¹⁶ irrespective of the actual wording in the article. This model focuses on older adults and, hence, does not consider the working situation, which might be an important source of social participation for younger people. We, therefore, assigned findings on the working situation to the aspect of (informal) social participation. Furthermore, the number of eligible articles differs with regard to the wound type and the aspect of social participation, which may limit the explanatory power. Additionally, the search revealed a mostly moderate methodological quality, especially in quantitative studies. Also, a large share of the relevant articles presents data from studies conducted in the United Kingdom. A reason for this might be the academisation of nursing, which is more advanced in the United Kingdom than in other countries.¹⁰⁰

Considering the positive effect social participation has on the individual's health, particularly older people,¹⁰¹⁻¹⁰³ it should receive more attention in clinical practice and public health. This includes the assessment of social support and the possibility to engage in social interactions as part of clinical care. For routine assessments in clinical care, a validated, short, and feasible, yet sufficiently comprehensive questionnaire would be needed.

A possibility to enhance social participation in patients with chronic wounds would be to strengthen the concept of Leg Clubs. Especially regarding patients' social interactions, Leg Clubs have shown positive impacts.¹⁰⁴ It might be promising to open the concept also for patients with other chronic wound aetiologies because patients' experiences barely differ, as found in this review. Following the approach in the United Kingdom, Leg Clubs have already been initiated in Australia and Germany.⁸⁸ However, differences between healthcare systems might impair the transferability of this concept.¹⁰⁴ For example, one Leg Club, which has been initiated in the German city of Munich, is located in a general practitioner's office and requires the physician to prescribe treatment; the project is based on the engagement of volunteers as it is not funded by German sick funds.¹⁰⁵

In routine care, social participation should receive increased attention both as a trigger of burden and as an outcome of therapy. For this, the patients' individual goal setting should be recognised and targeted with an individual treatment plan. One way to assess treatment goals of patients with chronic wounds is to use the Patient Benefit Index,¹⁰⁶ which also covers aspects of patients' social life.

This review revealed a high number of qualitative studies. Quantitative studies were not only less numerous but also of moderate quality only. In future research, emphasis should be placed on high-quality quantitative studies that include control groups of people without wounds. Nevertheless, the assessment of social participation should not be restricted to counting contacts and activities but should also consider the patients' perception of and confidence with aspects of their social lives, rather calling for mixed-methods studies. Following the finding that social participation is similar across different types of wounds, studies do not need to be restricted on one single wound aetiology but may investigate the social participation of different patients with diverse aetiologies simultaneously.

ACKNOWLEDGMENTS

The authors thank the Scientific Communication Team of the IVDP, in particular Merle Twesten and Mario Gehoff, for copy editing. This is an unfunded study. Open access funding enabled and organized by Projekt DEAL.

CONFLICT OF INTEREST

TMK, VA, NK, and CB have no conflict of interest. KP has received fees for consultations and/or presentations from the following companies: Bauerfeind, Bösl Medizintechnik, BSN medical/Essity, Coloplast, Convatec, DAK, GlaxoSmithKline, Hartmann, Lohmann & Rauscher, medi, Mölnlycke, Sanafactur, Schülke & Mayr, Uluru, URGO. MA has served as consultant and/ or paid speaker for and/or has received research grants -WILEY-

and/or honoraries for consulting and/or scientific lectures for and/or got travel expenses reimbursed and/or participated in clinical trials sponsored by companies that manufacture drugs used for the treatment of chronic wounds including 3M, AOK Bundesverband, Bayer Healthcare, Beiersdorf, Birken, Bode, B. Braun, BSN, BVmed, Coloplast, DAK, Diabet concept, Gerromed, GlaxoSmithKline, Johnson & Johnson, Lohmann & Rauscher, Medi, Medovent, Mölnlycke, Smith & Nephew, Schülke & Mayr, Söring, Sorbion, Systagenix, and Urgo.

DATA AVAILABILITY STATEMENT

The data are available on reasonable request from the corresponding author.

ORCID

Toni Maria Klein D https://orcid.org/0000-0002-9861-9519

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

REFERENCES

- Lazarus GS, Cooper DM, Knighton DR, et al. Definitions and guidelines for assessment of wounds and evaluation of healing. *Wound Repair Regen*. 1994;2:165-170.
- 2. Werdin F, Tennenhaus M, Schaller H-E, Rennekampff H-O. Evidence-based management strategies for treatment of chronic wounds. *Eplasty.* 2009;9:e19.
- 3. Mekkes JR, Loots MAM, van der Wal ACV, Bos JD. Causes, investigation and treatment of leg ulceration. *Br J Dermatol.* 2003;148:388-401.
- 4. Dissemond J, Bültemann A, Gerber V, Jäger B, Münter C, Kröger K. Definitionen für die Wundbehandlung (Definitions for wound treatment). *Hautarzt.* 2016;67:265-266.
- 5. Werdin F, Tenenhaus M, Rennekampff H-O. Chronic wound care. *Lancet*. 2008;372:1860-1862.
- Martinengo L, Olsson M, Bajpai R, et al. Prevalence of chronic wounds in the general population: systematic review and metaanalysis of observational studies. *Ann Epidemiol.* 2019;29:8-15.
- Heyer K, Herberger K, Protz K, Glaeske G, Augustin M. Epidemiology of chronic wounds in Germany: analysis of statutory health insurance data. *Wound Repair Regen*. 2016;24: 434-442.
- Wicke C, Bachinger A, Coerper S, Beckert S, Witte MB, Königsrainer A. Aging influences wound healing in patients with chronic lower extremity wounds treated in a specialized wound care center. *Wound Repair Regen*. 2009;17:25-33.
- Erickson CA, Lanza DJ, Karp DL, et al. Healing of venous ulcers in an ambulatory care program: the roles of chronic venous insuffiency and patient compliance. *J Vasc Surg.* 1995; 22:629-636.
- Dias TYAF, Costa IKF, Melo MDM, Torres SM d SGS d O, EMC M, GdV T. Quality of life assessment of patients with and without venous ulcer. *Rev Lat Am Enfermagem*. 2014;22: 576-581.

- 11. Sommer R, Augustin M, Hampel-Kalthoff C, Blome C. The wound-QoL questionnaire on quality of life in chronic wounds is highly reliable. *Wound Repair Regen*. 2017;25:730-732.
- 12. Brandenburg VM, Sinha S, Torregrosa J-V, et al. Improvement in wound healing, pain, and quality of life after 12 weeks of SNF472 treatment: a phase 2 open-label study of patients with calciphylaxis. *J Nephrol.* 2019;32:811-821.
- Edwards H, Finlayson K, Skerman H, et al. Identification of symptom clusters in patients with chronic venous leg ulcers. *J Pain Symptom Manage*. 2014;47:867-875.
- 14. Do HTT, Edwards H, Finlayson K. Identifying relationships between symptom clusters and quality of life in adults with chronic mixed venous and arterial leg ulcers. *Int Wound J.* 2016;13:904-911.
- 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;22:504-514.
- 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: 455-462.
- Jang Y, Park NS, Dominguez DD, Molinari V. Social engagement in older residents of assisted living facilities. *Aging Ment Health.* 2014;18:642-647.
- Martinson M, Minkler M. Civic engagement and older adults: a critical perspective. *Gerontologist*. 2006;46:318-324.
- Momtaz YA, Haron SA, Ibrahim R, Hamid TA. Social embeddedness as a mechanism for linking social cohesion to well-being among older adults: moderating effect of gender. *Clin Interv Aging*. 2014;9:863-870.
- Young FW, Glasgow N. Voluntary Social participation and health. *Res Aging*. 1998;20:339-362.
- Zunzunegui M-V, Alvarado BE, Del Ser T, Otero A. Social networks, social integration, and social engagement determine Cognitive decline in community-dwelling Spanish older adults. *J Gerontol.* 2003;58B:S93-S100.
- 22. Cohen S, Wills TA. Stress, social support, and the buffering hypothesis. *Psychol Bull*. 1985;98:310-357.
- 23. Berkman LF. The role of social relations in health promotion. *Psychosom Med.* 1995;57:245-254.
- Kuzuya M, Enoki H, Hasegawa J, et al. Impact of caregiver burden on adverse health outcomes in community-dwelling dependent older care recipients. *Am J Geriatr Psychiatry*. 2011;19:382-391.
- 25. da Silva DC, Budó, Maria de Lourdes Denardin, Schimith MD, Torres GdV, Durgante VL Rizzatti, Salete de Jesus Souza, Simons BS. Influence of social networks on the therapeutic itineraries of people with venous ulcer. *Rev Gaucha Enferm* 2014;35:90-96.
- 26. Wise G. The social ulcer. Nurs Times. 1986;82:47-49.
- Brown A. Does social support impact on venous ulcer healing or recurrence? *Br J Community Nurs.* 2008;13:s6-s14. S6, S8, S10 passim.
- Levasseur M, Desrosiers J, DS-C T. Comparing the disability creation process and international classification of functioning, disability and health models. *Can J Occup Ther.* 2007;74: 233-242.

- 29. 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;51:16-30.
- 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;25:409-414.
- Lacerda FKL, de Santana Carvalho ES, de Araújo Dias AL, de Araújo EM, de Amorim Miranda NB, Almeida TA. Women with sickle anemia living with leg ulcers and pain. *Rev Enfermagem Ufpe*. 2014;8:2054-2060.
- 32. Neil J, Munjas B. Living with a chronic wound: the voices of sufferers. *Ostomy Wound Manage*. 2000;46:28-38.
- Ousey K, Stephenson J, Barret S, et al. Wound care in five English NHS trusts: results of a survey. *Wounds UK*. 2013;9:20-28.
- Bukov A, Ineke M, Lampert T. Social participation in very old age: cross-sectional and longitudinal findings from BASE. *J Gerontol.* 2002;57B:P510-P517.
- 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;57:1175-1183.
- Herber OR, Schnepp W, Rieger MA. A systematic review on the impact of leg ulceration on patients' quality of life. *Health Qual Life Outcomes*. 2007;5:1-12.
- Green J, Jester R. Health-related quality of life and chronic venous leg ulceration: part 1. *Br J Community Nurs*. 2009;14: S12-S17.
- Parker K. Psychosocial effects of living with a leg ulcer. Nurs Stand. 2012;26:52-62.
- Persoon A, Heinen MM, van der Vleuten CJM, Rooij MJ d, PCM v d K, van Achterberg T. Leg ulcers: a review of their impact on daily life. *J Clin Nurs*. 2004;13:341-354.
- 40. Green J, Jester R, McKinley R, Pooler A. The impact of chronic venous leg ulcers: a systematic review. *J Wound Care*. 2014;23:601-612.
- 41. Phillips P, Lumley E, Duncan R, et al. A systematic review of qualitative research into people's experiences of living with venous leg ulcers. *J Adv Nurs*. 2018;74:550-563.
- 42. Fearns N, Heller-Murphy S, Kelly J, Harbour J. Placing the patient at the centre of chronic wound care: a qualitative evidence synthesis. *J Tissue Viability*. 2017;26:254-259.
- Domingues EAR, Cavalcanti MCESL, PCPd C, MHBdM L, Monteiro I, NMC A. Pain prevalence, socio-demographic and clinical features in patients with chronic ulcers. *J Tissue Viability*. 2016;25:180-184.
- 44. Järbrink K, Ni G, Sönnergren H, et al. Prevalence and incidence of chronic wounds and related complications: a protocol for a systematic review. *Syst Rev.* 2016;5:152.
- Kranke P, Bennett MH, Martyn-St James M, Schnabel A, Debus SE, Weibel S. Hyperbaric oxygen therapy for chronic wounds. *Cochrane Database Syst Rev.* 2015;CD004123(6). http://doi.org/10.1002/14651858.CD004123.pub4.
- Martinez-Zapata MJ, Martí-Carvajal AJ, Solà I, et al. Autologous platelet-rich plasma for treating chronic wounds. *Cochrane Database Syst Rev.* 2016;CD006899(5). http://doi. org/10.1002/14651858.CD006899.pub3.
- 47. Cordier R, Milbourn B, Martin R, Buchanan A, Chung D, Speyer R. A systematic review evaluating the psychometric

properties of measures of social inclusion. *PLoS One*. 2017;12: e0179109.

IWJ

LWILEY.

- Gariépy G, Honkaniemi H, Quesnel-Vallée A. Social support and protection from depression: systematic review of current findings in Western countries. *Br J Psychiatry*. 2016;209: 284-293.
- Owuor J, Larkan F, Kayabu B, et al. Does assistive technology contribute to social inclusion for people with intellectual disability? A systematic review protocol. *BMJ Open.* 2018;8: e017533.
- Brown A. Chronic leg ulcers, part 2: Do they affect a patient's social life? *Br J Nurs*. 2005;14:986-989.
- Adni T, Martin K, Mudge E. The psychosocial impact of chronic wounds on patients with severe epidermolysis bullosa. *J Wound Care*. 2012;21:528-538.
- Bandeira LA, dos Santos MC, ÊRM D, Bandeira AG, Riquinho DL, Vieira LB. Social networks of patients with chronic skin lesions: nursing care. *Rev Bras Enferm.* 2018;71:652-659.
- Brod M. Quality of life issues in patients with diabetes and lower extremity ulcers: patients and care givers. *Qual Life Res.* 1998;7:365-372.
- da Silva DC, MdL B, Schimith MD, Ecco L, IKF C, GdV T. Experiences constructed in the process of living with a venous ulcer. *Cogitare Enfermagem*. 2015;20:13-19.
- 55. da Silva MH, de Jesus MCP, MAB M, de Oliveira DM, Biscotto PR, GPS S. The daily life of men who lives with chronic venous ulcer: phenomenological study. *Rev Gaucha Enferm.* 2013;34:95-101.
- 56. Firth J, Nelson EA, Briggs M, Gorecki C. A qualitative study to explore the impact of foot ulceration on health-related quality of life in patients with rheumatoid arthritis. *Int J Nurs Stud.* 2011;48:1401-1408.
- 57. Fox C. Living with a pressure ulcer: a descriptive study of patients' experiences. *Br J Community Nurs*. 2002;7:10-14.
- Garcia AB, Müller PV, PdO P, ÊRM D, Kaiser DE. Perception of users on self-care of lower leg ulcers. *Rev Gaucha Enferm*. 2018;39:1-19.
- Hopkins A. Disrupted lives: investigating coping strategies for non-healing leg ulcers. *Br J Nurs*. 2004;13:556-563.
- 60. Hyde C, Ward B, Horsfall J, Winder G. Older women's experience of living with chronic leg ulceration. *Int J Nurs Pract.* 1999;5:189-198.
- 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.
- Palfreyman SJ, Tod AM, King B, Tomlinson D, Brazier JE, Michaels JA. Impact of intravenous drug use on quality of life for patients with venous ulcers. *J Adv Nurs*. 2007;58:458-467.
- 63. 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;19:345-355.
- 64. Searle A, Campbell R, Tallon D, Fitzgerald A, Vedhara K. Psychosocial aspects in wound care. A qualitative approach to understanding the experience of ulceration and healing in the diabetic foot: patient and podiatrist perspectives. *Wounds*. 2005;17:16-26.

- 65. Bradbury SE, Price P. Diabetic foot ulcer pain: the hidden burden (part two). *Ewma J.* 2011;11:25-37.
- 66. Byrne O, Kelly M. Living with a crhonic leg ulcer. *J Community Nurs.* 2010;24:46-54.
- Hopkins A, Dealey C, Bale S, Defloor T, Worboys F. Patient stories of living with a pressure ulcer. J Adv Nurs. 2006;56:345-353.
- 68. Langemo D, Melland H, Hanson D, Olson B. The lived experience of having a pressure ulcer: a qualitative analysis. *Adv Skin Wound Care.* 2000;13:225-235.
- Rich A, McLachian L. How living with a leg ulcer affects people's daily life: a nurse-led study. J Wound Care. 2003;12:51-54.
- Akca AT, Cinar S. Comparison of psychosocial adjustment in people with diabetes with and without diabetic foot ulceration. *Aust J Adv Nurs*. 2008;25:87-96.
- Figueira ALG, Boas LCGV, de Freitas MCF, Foss MC, Pace AE. Perception of social support by individuals with diabetes mellitus and foot ulcers. *Acta Paul Enferm.* 2012;25:20-26.
- Flett R, Harcourt B, Alpass F. Psychosocial aspects of chronic lower leg ulceration in the elderly. *West J Nurs Res.* 1994;16: 183-192.
- Kouris A, Armyra K, Christodoulou C, et al. Quality of life psychosocial characteristics in Greek patients with leg ulcers: a case control study. *Int Wound J.* 2016;13:744-747.
- Kouris A, Christodoulou C, Efstathiou V, et al. Comparative study of quality of life and psychosocial characteristics in patients with psoriasis and leg ulcers. *Wound Repair Regen*. 2016;24:443-446.
- Moffatt CJ, Franks PJ, Doherty DC, Smithdale R, Steptoe A. Psychological factors in leg ulceration: a case-control study. *Br J Dermatol.* 2009;161:750-756.
- Morgan PA, Franks PJ, Moffatt CJ, et al. Illness behavior and social support in patients with chronic venous ulcers. *Ostomy Wound Manage*. 2004;50:25-32.
- Septiana MN, Gayatri D. The impact of discomfort: physical and psychological to social interaction in diabetic ulcer patients in Jakarta – Indonesia. *Enferm Clin.* 2019;29:407-412.
- 78. Wissing U, Ek AC, Unosson M. Life situation and function in elderly people with and without leg ulcers. *Scand J Caring Sci.* 2002;16:59-65.
- 79. 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.
- Franks PJ, Moffatt CJ. Who suffers most from leg ulceration? J Wound Care. 1998;7:383-385.
- 81. Franks PJ, Moffatt CJ. Do clinical and social factors predict quality of life in leg ulceration? *Int J Low Extrem Wounds*. 2006;5:236-243.
- Pieper B, Szczepaniak K, Templin T. Psychosocial adjustment, coping, and quality of life in persons with venous ulcers and a history of intravenous drug use. *J Wound Ostomy Continence Nurs*. 2000;27:227-237.
- Charles H. The influence of social support on leg ulcer healing. Br J Community Nurs. 2010;15:S14-S21.
- Keeling D, Price P, Jones E, Harding KG. Social support for elderly patients with chronic wounds. *J Wound Care*. 1997;6: 389-391.
- Upton D, Upton P, Alexander R. Contribution of the Leg Club model of care to the well-being of people living with chronic wounds. *J Wound Care*. 2015;24:397-405.

- Hareendran A, Bradbury A, Budd J, et al. Measuring the impact of venous leg ulcers on quality of life. *J Wound Care*. 2005;14:53-57.
- Lindsay E. The Lindsay Leg Club Model: a model for evidence-based leg ulcer management. *Br J Community Nurs*. 2004;Sup2:S15-S20.
- The Lindsay Leg Club® Foundation. Leg Club® Directories. 2020 https://www.legclub.org/. Accessed May 25, 2020.
- Russell D, Peplau LA, Cutrona CE. The revised UCLA loneliness scale: concurrent and discriminant validity evidence. *J Pers Soc Psychol.* 1980;39:472-480.
- Barrera M, Sandler IN, Ramsay TB. Preliminary development of a scale of social support: studies on college students. *Am J Community Psychol.* 1981;9:435-447.
- 91. Sherborne CD, Stewart AL. The MOS social support survey. *Soc Sci Med.* 1991;32:705-714.
- 92. Jockenhöfer F, Gollnick H, Herberger K, et al. Aetiology, comorbidities and cofactors of chronic leg ulcers: retrospective evaluation of 1 000 patients from 10 specialised dermatological wound care centers in Germany. *Int Wound J.* 2016;13: 821-828.
- 93. Reinhard SC, Levine C, Samis S. Home alone: family caregivers providing complex chronic care https://www.aarp.org/ content/dam/aarp/research/public_policy_institute/health/ home-alone-family-caregivers-providing-complex-chroniccare-rev-AARP-ppi-health.pdf. Accessed May 25, 2020.
- Gillick MR. The critical role of caregivers in achieving patient-centered care. JAMA. 2013;310:575-576.
- Nabuurs-Franssen MH, Huijberts MSP, Nieuwenhuijzen Kruseman AC, Willems J, Schaper NC. Health-related quality of life of diabetic foot ulcer patients and their caregivers. *Diabetologia*. 2005;48:1906-1910.
- Adelman RD, Tmanova LL, Delgado D, Dion S, Lachs MS. Caregiver burden: a clinical review. JAMA. 2014;311:1052-1060.
- Victor C, Scambler S, Bond J, Bowling A. Loneliness in later life: preliminary findings from the growing older project. *Quality Ageing Policy Pract Res.* 2002;3:34-41.
- 98. Kapp S, Santamaria N. How and why patients self-treat chronic wounds. *Int Wound J.* 2017;14:1269-1275.
- Reinhard SC, Given B, Petlick NH, Bemis A. Supporting family caregivers in providing care. In: Hughes RG, ed. *Patient Safety* and *Quality: An Evidence-Based Handbook for Nurses*. Rockville, MD: Agency for Healthcare Research and Quality; 2008.
- 100. Lehmann Y, Behrens J. Akademisierung der Ausbildung und weitere Strategien gegen Pflegepersonalmangel in europäischen Ländern. In: Jacobs K, Kuhlmeyer A, Greß S, Klauber J, Schwinger A, eds. *Pflege-Report 2016- Die Pflegenden im Fokus*. Schattauer: Stuttgart; 2016:51-71.
- Leone T, Hessel P. The effect of social participation on the subjective and objective health status of the over-fifties: evidence from SHARE. *Ageing Soc.* 2016;36:968-987.
- 102. Minagawa Y, Saito Y. Active social participation and mortality risk among older people in Japan: results from a nationally representative sample. *Res Aging*. 2015;37:481-499.
- 103. Thraen-Borowski KM, Trentham-Dietz A, Edwards DF, Koltyn KF, Colbert LH. Dose-response relationships between physical activity, social participation, and health-related quality of life in colorectal cancer survivors. *J Cancer Surviv.* 2013; 7:369-378.

- 104. Abu Ghazaleh H, Artom M. Sturt J. a systematic review of community leg clubs for patients with chronic leg ulcers. *Prim Health Care Res Dev.* 2018;20(e65):1-10.
- 105. Kaiser-Matner B. Der LEG CLUB als Modell zur Qualitätssicherung in der ambulanten Wundversorgung. Ein Konzept für konstante, professionelle Versorgung für Menschen mit chronischen Wunden. https://www.wundzentrum-hamburg. de/wp-content/uploads/2019/11/05.09.2019_B._Kaiser-Matner_ Das_Modell_Leg_Club.pdf. Accessed May 25, 2020.
- 106. Augustin M, Blome C, Zschocke I, et al. Benefit evaluation in the therapy of chronic wounds from the patients' perspectivedevelopment and validation of a new method. *Wound Repair Regen.* 2012;20:8-14.

SUPPORTING INFORMATION

Additional supporting information may be found online in the Supporting Information section at the end of this article.

How to cite this article: 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: 287–311. https://doi.org/10.1111/iwj.13533