Published in final edited form as:
*Pain*. 2022 March 01; 163(3): e426–e431. doi:10.1097/j.pain.0000000000002404.

# Beyond pain, distress, and disability: the importance of social outcomes in pain management research and practice

**Claire E. Ashton-James**#1, **Steven R. Anderson**#2, **Sean C. Mackey**#2, **Beth D. Darnall**#2

[1] Pain Management Research Institute, School of Medicine, Faculty of Medicine and Health, The University of Sydney Sydney, Australia.

[2] Division of Pain Medicine, Department of Anesthesiology, Perioperative and Pain Medicine, Stanford University School of Medicine, Stanford, USA.

# These authors contributed equally to this work.

**Keywords**

Social aspects of pain; social functioning; measurement; patient-centred care; treatment effectiveness

The success of multimodal chronic pain management is typically measured by changes in pain intensity, psychological distress, and disability (physical function and activity interference) [23,28,48,119]. Pain, distress, and disability are vitally important therapeutic targets. However, the social outcomes of pain - profoundly influencing both patients' experience of chronic pain and quality of life [22,24,38,60] – are equally important from a clinical perspective, and may even be more important therapeutic targets from the patient and their families' perspective. We argue for expanded measurement of the social consequences of pain in clinical research and practice, including satisfaction with social roles, perceived injustice, dyadic and family relationship functioning, social connectedness, and social support. More systematic and comprehensive measurement will allow us to evaluate the therapeutic impact of pain management on patients' social outcomes, and the contribution of social outcomes to patients' experience of pain, distress, and disability.

## The social consequences of pain

The experience of chronic pain is associated with withdrawal from social activity [123], increased social isolation [126], feelings of loneliness [1,2,73], and the erosion of social identity [67]. These social consequences of pain can create feelings of guilt and worry which further heighten distress and impede pain self-care [134,135]. The "invisible" nature of chronic pain conditions (where pain persists after the visible healing of injury) can give rise to misunderstandings, mistrust, and workplace conflict, precipitate stigmatization, discrimination, and bullying [36,91,113,125], and exacerbate social and

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*Corresponding author:* Associate Professor Claire Ashton-James, Pain Management Research Institute, The University of Sydney, School of Medicine - Northern Clinical School, Lvl 2 Douglas Building, Royal North Shore Hospital, St Leonards, Australia, 2065.

Conflicts of Interest.
The authors have no conflicts of interest to disclose.

economic inequalities [3,20]. Pain can give rise to feelings of hostility [2], which may precipitate conflict between spouses [11,35,69,70,80] and dysfunction within families [46,95]. Having a primary caregiver with chronic pain is associated with poorer psychosocial functioning [132] and higher risk of acquiring chronic pain in children [50]. Taken together, it is clear that the consequences of chronic pain extend beyond distress and disability, and indeed beyond the individual, to affect the social lives of the person with pain and their family. These social experiences can, in turn, perpetuate and exacerbate pain, distress, and disability (Fig. 1).

## Social pains can affect treatment gains

Increasingly, researchers, clinicians, and public health organizations are recognizing the importance of relationship quality and social safety for health, wellbeing, and quality of life [8,51,76,110]. Strong supportive relationships are associated with greater adherence to treatment advice [25], hastened recovery from illness and injury [71,89], lower likelihood of developing chronic pain [103], lower stress [16], and higher subjective wellbeing [68]. By contrast, ‘social pains’ such as perceived social isolation, social exclusion, and feelings of loneliness are associated with reduced physical activity [45], disrupted sleep [9], increased pro-inflammatory activity [30], diminished immunity [26,96], and a range of chronic diseases including diabetes, cardiovascular disease, depression, and chronic pain [1,6,10]. Accordingly, for people living with chronic pain, social isolation and low perceived social support is associated with worsening pain, distress, and disability over time [18,33,44,59,63,70,75]. Cross-lagged longitudinal analyses reveal that patient-reported social isolation is associated with later pain interference, but not vice versa [59]. Hence, social impacts of pain management (e.g., restoration of social roles, relationships, and increased social integration) may be critical to the achievement and maintenance of therapeutic gains.

## Social outcomes are patient-centred outcomes

Importantly, improved social relationships may be a primary goal of pain management for patients. In a survey of 800 patients with chronic pain, two-thirds rated social outcomes as “extremely important” [122]. Similarly, when asked what “recovery” meant to them, patients pointed to reduced pain and increased quality of life, including more satisfying relationships with others [52]. Consistent with these findings, a recent survey revealed that participation in social and family activities is among the most valued outcomes of chronic pain management [137]. These studies converge with research indicating that patient wellbeing and quality of life is not merely a matter of improved pain and physical functioning. Indeed, Sturgeon and colleagues [116] found that disruption to social relationships mediated the relationship between impaired physical functioning and emotional distress, indicating that satisfaction with social roles and relationships may be a more salient predictor of emotional wellbeing than physical functioning in patients with chronic pain.

## Barriers to the measurement of social outcomes in pain management

The importance of social outcomes in the treatment of chronic pain is clear. It follows that social outcomes should be prioritised in the evaluation of pain management effectiveness. However, when the Initiative on Methods, Measurement, and Pain Assessment in Clinical Trials (IMMPACT) recommended core outcome measures for chronic pain clinical trials, interpersonal relationship functioning measures were not included among them [28]. Perhaps as a consequence, a recent systematic review [23] of 70 studies of multimodal pain therapy found that the most commonly reported outcomes were pain intensity, depressive symptoms, and physical functioning, with satisfaction with social roles and relationships reported in less than 10% of studies. Consistent with this, a 2020 survey of healthcare providers working in tertiary pain clinics found that social health outcomes were measured far less frequently than physical and mental health outcomes [137].

It is possible that the absence of social outcome measures in pain management research and practice reflects a lack of awareness of valid, reliable, and clinically relevant social outcome measures [137]. To assist clinicians and researchers in implementing social outcome measures we provide a selection of validated measures in Table 1. These measures can be accessed from the journals in which they are published, and map on to the social outcome domains that patients with chronic pain feel are most pertinent to their recovery: satisfaction with social roles and relationships, relationship functioning, family functioning, social connectedness, social support, perceived injustice, and self-care. As noted above, there is a bidirectional relationship between social experiences and pain, distress, and disability [19,73,86] (see also Figure 1). Hence, in a clinical context, what we have described here as social outcome measures may also be used to evaluate social contributors to pain and identify patients who might derive most benefit from interventions targeting social functioning (e.g., online peer-support groups [77]; relationship counselling [111]; family therapy [94]; communication skills training [74]).

An additional barrier to the implementation of social outcome measures may be clinicians' tendency to take a unidimensional approach to pain management. In a survey of healthcare providers in tertiary, multidisciplinary pain clinics [137], 89% responded that patients' social health was not relevant to their clinical practice or was outside their scope of practice. This highlights the importance of increasing healthcare education efforts to further develop trainee understanding of and competence in identifying and managing social aspects of pain. Indeed, healthcare providers' lack of understanding and responsiveness to the social determinants and consequences of pain may be perpetuating unconscious bias and stigma, and contributing to patients feeling disconnected from healthcare providers.

A more troubling explanation for the absence of social outcome measures in pain management research and practice may be that clinician-researchers are reluctant to know what these measures reveal about our current pain treatments' effectiveness. The effect sizes of multidisciplinary pain management programs on pain, distress, and disability are small to moderate [57], but their effectiveness for relieving social suffering is unknown. It may be that multidisciplinary pain management programs improve the quality of patients' social relationships by improving mood and increasing participation in social activities. However, it is also possible that the damage inflicted on patients' social functioning cannot be mended *indirectly* via interventions targeted at reducing pain, distress, and disability, but instead requires interventions *directly* targeting repairing social relationships and connections (e.g., spouse-assisted coping skills training, conflict negotiation [12,61,79]). Multidisciplinary approaches to pain management purport to be biopsychosocial [53], but it is possible that they are failing to adequately address the social aspects of pain in meaningful ways. Documenting unmet patient needs through greater measurement of social outcomes may enhance future advocacy efforts to include social-based treatment interventions.

Finally, the relative absence of social outcome measures in pain management research and practice may reflect a pervasive tendency for outcome measures to be clinician-centred rather than patient-centred. A fundamental principle of patient-centred care is that patients are engaged the development of treatment goals that are meaningful to them. Table 1 offers clinicians and researchers a number of options for measuring social outcomes across a variety of domains that have been demonstrated to contribute to the trajectory of chronic pain and patients' day to day quality of life. Consistent with a co-production model of research and clinical care [29,64,121], we recommend that clinicians and researchers take a patient-centered approach to selecting social outcome measures, engaging with patients to determine which of these social outcome domains are most relevant for the individual or study cohort. Future studies should focus on the relative importance of each of the identified outcome domains from the patient's perspective.

## Conclusion

Although improved social outcomes are a critical goal of pain management for patients, the social outcomes of pain management are rarely evaluated. Failing to adequately address the social functioning of patients with chronic pain may hamper the longterm effectiveness of interventions, and may be a missed opportunity to mitigate the risk of intergenerational transmission of pain within families. With greater awareness of and access to validated social outcome measures, we hope to see greater scrutiny of the social outcomes of interventions for the management of chronic pain.

## Acknowledgements

This study was supported by grants from the National Institute on Drug Abuse (T32DA035165 and K24DA029262). The content is solely the responsibility of the authors and does not necessarily represent the official views of the National Institutes of Health.

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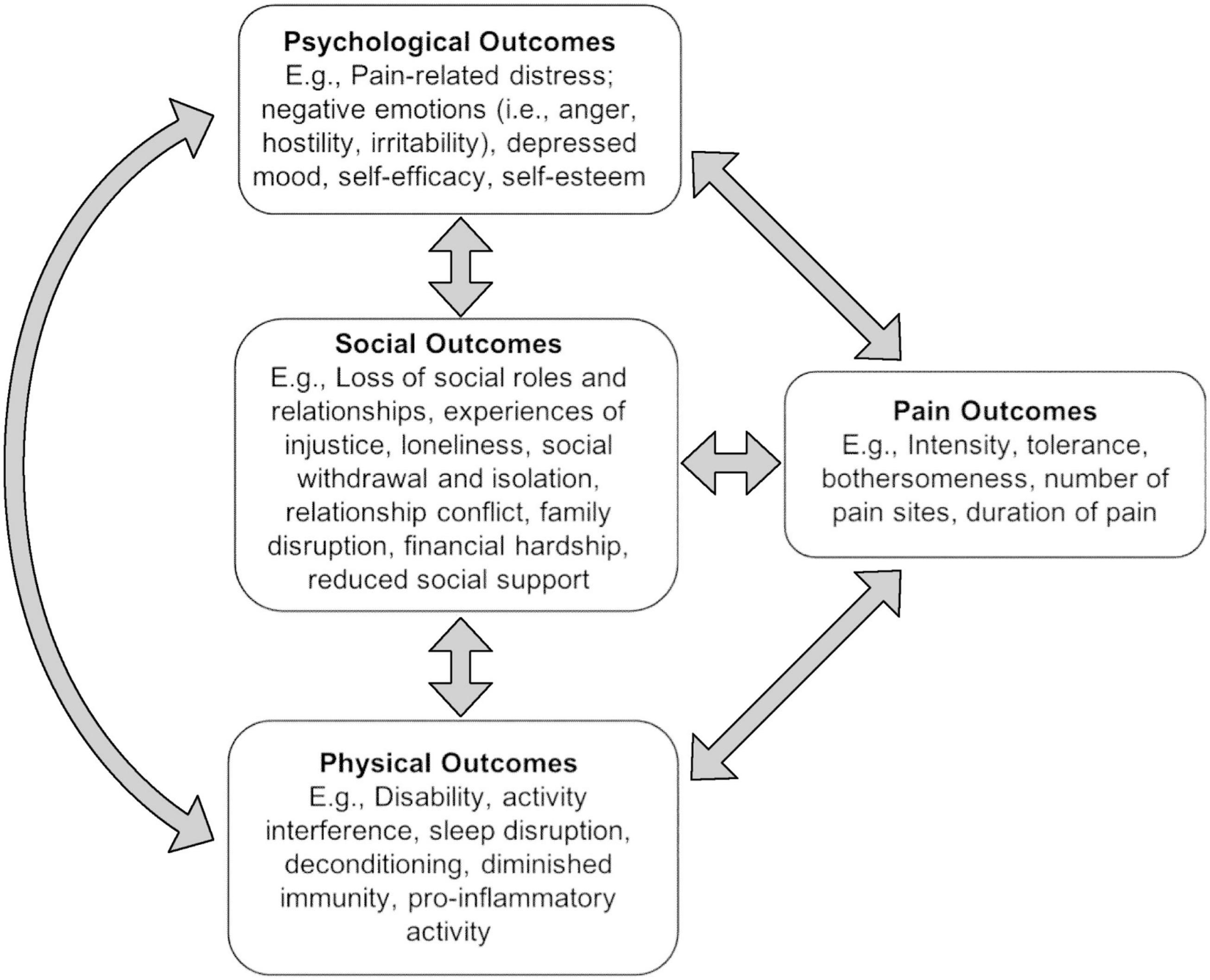

**Figure 1.**

Relationship between psychological, social, and physical outcomes and pain.

## Table 1.

Examples of clinically validated measures of social outcomes.

| Development Study | Instrument Name | Number of Items | Reliability | Chronic Illness Condition |
|---|---|---|---|---|
| **Satisfaction with Social Roles and Relationships** | | | | |
| Hahn et al. [42]; Castel et al. [15] | PROMIS Satisfaction with Social Roles and Activities (v2.0) | 44 (CAT); 4, 6, 8 (Short Forms) | >.98 | Individuals with chronic heart failure, chronic obstructive pulmonary disease, chronic back pain, or depression [41]; individuals with chronic pain [116]; individuals undergoing outpatient rehabilitation [118] |
| **Relationship Functioning** | | | | |
| Spanier [112]; Carey et al. [14] | Dyadic Adjustment Scale (DAS) | 32 | .70 – .95 | Individuals with chronic low back pain [130]; couples with chronic pain [84] |
| Busby et al. [7] | Dyadic Adjustment Scale - Revised (RDAS) | 14 | .90 | Individuals with chronic pain [17]; women with vestibulodynia [56] |
| Sabourin et al. [104] | Dyadic Adjustment Scale - Brief Version (DAS-4) | 4 | .84 | Couples with vulvodynia [101]; partners of men treated for prostate cancer [43] |
| Schwartz et al. [107] | Spouse Response Inventory (SRI) | 26 | .81 – .93 | Individuals with chronic pain [97] |
| Kerns et al. [62] | West-Haven Yale Multidimensional Pain Inventory (WHYMPI) – Part II | 14 | .74 – .84 | Individuals with chronic pain [13,34]; individuals with chronic fatigue syndrome [106]; individuals with coronary heart disease [54] |
| Locke and Wallace [72] | Locke-Wallace Marital Adjustment Test (MAT) | 15 | .90 | Individuals with chronic pain [13,34]; individuals with osteoarthritis [78,99]; couples seeking treatment for infertility [88] |
| **Family Functioning** | | | | |
| Epstein et al. [32]; Miller et al. [83] | McMaster Family Assessment Device (FAD) | 60 | .66 – .76 | Children with chronic illness conditions [49]; children with pediatric sickle cell disease [85] |
| **Social Connectedness** | | | | |
| **Van Orden et al.** [124]; Freedenthal et al. [37] | Interpersonal Needs Questionnaire (INQ-12) | 12 | >.90 | Individuals with chronic pain [58,133] |
| Hahn et al. [42] | PROMIS Social Isolation | 14 (CAT); 4, 6, 8 (Short Forms) | >.98 | Individuals with chronic pain [59,115,136] |
| Russell [102]; Hays and DiMatteo [47] | UCLA Loneliness Scale (Version 3); ULS-8 | 20 | .89 – .94; .77 | Breast cancer survivors [55] |
| Gierveld and Tilburg [39] | De Jong Gierveld Loneliness Scale | 6 | .71 – .76 | Individuals with rheumatoid arthritis [127] |
| **Social Support** | | | | |
| Broadhead et al. [4] | Duke-UNC Functional Social Support Questionnaire | 14 | .92 | Individuals with rheumatic disease [109]; individuals with chronic pain [75] |
| Sarason et al. [105] | Brief Social Support Questionnaire (SSQ6) | 6 | .90 – .93 | Individuals with spinal cord injury [114] |
| **Zimet et al.** [138]; [139] | Multidimensional Scale of Perceived Social Support (MSPSS) | 12 | .85 – .91 | Individuals with multiple sclerosis [93] |

| **Development Study** | **Instrument Name** | **Number of Items** | **Reliability** | **Chronic Illness Condition** |
|---|---|---|---|---|
| **Ware Jr and Sherbourne** [128]; McHorney et al. [81] | SF-36 Social Functioning Scale | 36 | .85 | Individuals with chronic pain [31] |
| Dowrick et al. [27]; Meltzer [82]; Dalgard [21] | Oslo Social Support Scale (OSSS-3) | 3 | .66 | Individuals with chronic pain [90] |
| Hahn et al. [42]; Castel et al. [15] | PROMIS Emotional Support | 16 (CAT); 4, 6, 8 (Short Forms) | >.98 | Individuals with upper extremity disability [92]; individuals with chronic pain [66] |
| **Perceived Injustice** | | | | |
| **Sullivan et al.** [117] | Injustice Experiences Questionnaire (IEQ) | 12 | .92 | Individuals with chronic pain [115,117,136], individuals who have experienced traumatic injury [120] |
| Waugh et al. [129]; Ritsher et al. [100] | Internalized Stigma of Chronic Pain Scale | 28 | .90 | Individuals with chronic pain [129]; individuals living with HIV and chronic pain [40] |
| Molina et al. [87]; Rao et al. [98] | Stigma Scale for Chronic Illness (SSCI-8) | 8 | .89 | Individuals with chronic pain [108] |
| Williams et al. [131]; Kessler et al. [65] | Lifetime Perceived Discrimination Scale | 11 | .92 | Individuals with chronic pain [5] |
| Williams et al. [131]; Kessler et al. [65] | Daily Perceived Discrimination Scale | 9 | .70 – .93 | Individuals with chronic pain [5] |
| **Factors Impacting Self-Care** | | | | |
| Ziadni et al. [135]; Ziadni et al. [134] | CARE Scale - 7 | 7 | .81 | Individuals with mixed etiology chronic pain [134,135] |

*Note*: These social outcome measures may also be used to assess social contributors to pain, distress, and disability.