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Assessing the Pain of Care Recipients: Tools Available to Family Caregivers

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Chronic pain is one of the most common factors affecting mobility and daily functioning in the US.

ABSTRACT

Care recipients who experience frequent or chronic pain due to their long-term physical conditions often rely on help from family caregivers to manage that pain. Although pain can present in a variety of conditions, the added challenge for family caregivers in assessing and managing their family member's pain contributes to caregiver burden, especially when they are not provided the proper support. A rapid review of literature between 2019 and 2022 was conducted in four electronic databases, Deepdyve, PubMed, Google Scholar, and the Cochrane Database of Systematic Reviews. A total of nine studies were selected for review. Pain is a common outcome measured across multiple conditions, yet no specific tools have been developed for assessment by family caregivers. The complex nature of pain management necessitates accessible and simple tools, as well as education and training for family caregivers to adequately assess and support family members.

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BACKGROUND

Chronic pain is generally accepted as pain that persists longer than 3 months (National Institute on Aging, 2022). Chronic pain is one of the most common factors affecting mobility and daily functioning in the US (Zelaya et al., 2020) impacting an estimated 50 million people (Zelaya et al., 2020) at a cost of 300 billion dollars annually (Yong et al., 2022). Although anyone can be affected by pain, it is most common among older adults (65+), white Americans, and among women (National Institute on Aging, 2022; Zelaya et al., 2020). Individuals who experience frequent or chronic pain due to their long-term physical conditions often require additional assistance from family caregivers, particularly in assessing

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and managing pain. However, pain management can be stressful for caregivers, especially when they are not provided the proper support. Pain management is a multilayered process often including tasks such as medication administration, tracking and managing regimens, monitoring for side effects, and communication with team members (Chi et al., 2020).

Over 60% of caregivers are caring for an adult with a long-term physical condition with older adult care recipients more likely to have such conditions (AARP & National Alliance for Caregiving, 2020). According to the Caregiving in the US 2020 study, 12% of caregivers are caring for someone with mobility conditions, 11% are caring for someone with Alzheimer's disease, 6% are caring for someone with cancer (AARP & National Alliance for Caregiving, 2020) – all conditions that are often associated with chronic pain. Further, more than eight out

of 10 caregivers are responsible for performing medical nursing tasks – skilled and complex care activities such as catheter care, tube feedings, etc. (Reinhard et al., 2019), and 50% of caregivers report they give medications, pills or injections (AARP & National Alliance for Caregiving, 2020). In addition, almost 70% assist with pain management or managing discomfort, one of the most stressful tasks caregivers assist with (Reinhard et al., 2019). In part, watching a family member or friend suffer and not being able to provide assistance or help control pain, as well as the fear of making a mistake (Reinhard et al., 2019) all contribute to the stress caregivers feel. Worse still, is the prospect of causing pain through varied medication, or care-related tasks ((Reinhard et al., 2019). Finally, acknowledging that some care partners may not share their true experience of pain to protect the caregiver adds to caregiver stress (Reinhard et al., 2019).

In order for caregivers to better manage pain, adequate support and tools are needed for pain assessment. The purpose of this literature review is to answer the primary question about caregivers who are caring for a family member experiencing pain: *What tools do family caregivers have to assess pain in family members?*

METHODS

A systematic process for a rapid review of the literature was conducted in April 2022 to determine available literature. Search strategies were developed with input and guidance from a master's prepared team member with expertise in library sciences. Relevant articles from a prior review conducted in December 2021on family caregivers and pain management were also examined. A combination of search terms included "family caregiver" "informal caregiver" "care partner" "pain identification" "pain management" "pain assessment"

"pain resources" and "pain tools" in Deepdyve, PubMed, Google Scholar, and the Cochrane Database of Systematic Reviews electronic databases. All available literature published from Jan 2019 through March 31, 2022 were searched. Inclusion criteria were as follows: 1) US study, 2) English language, 3) family caregivers, and 4) feasibility studies, pilot studies, descriptive studies, program, intervention/RCT, or review. Articles were added to rayyan.ai © software for de-duplication, plus abstract and full text screening. Rayyan.ai ©, a free web-based platform was used specifically for identifying duplicate articles and screening. It is one of two known available tools to assist in some steps of the systematic review workflow process. The initial search yielded 108 articles. Duplicates were removed and abstracts were reviewed according to inclusion criteria. Forty-one full text articles were assessed for eligibility. A total of nine articles were identified and included in this review.

FINDINGS

Nine studies were published in eight journals covering varied areas including *research, pain, cancer, hospice and palliative care, gerontology,* and *anesthesia*. Most studies were in community settings including home hospice, oncology clinics, and hospice and/or palliative care clinics. All studies included family caregivers, where five included patient and family caregiver dyads. Three studies included over 100 participants, three studies included participants or reviewed studies ranging between from 50-100 participants, and three studies included participants or reviewed studies at, or below, 25 participants. Three studies were systematic reviews, one was a multi-site randomized controlled trial (RCT), one was a secondary analysis of a RCT, one was an exploratory study, and three were pilot/feasibility studies. Three studies did not report

participant characteristics. One study included African American dyads, and of the remaining studies the majority included non-Hispanic/Latino white participants with one study comprised of Veteran's, and another containing a rural sample.

SUMMARY

The purpose of this review was to determine what tools were available to family caregivers for pain assessment. Tools for pain assessment have been used for decades in a variety of clinical, research, and community settings to measure pain across varied conditions, without implications or accessibility for general family caregiver usage.

The most common tool used in the articles reviewed was the Brief Pain Inventory (BPI) which has been implemented in cancer literature as well as dementia (Amspoker et al., 2021; Porter et al., 2021; Yeager et al., 2022). The BPI is an assessment with demonstrated reliability and validity, wide usability across racial/ethnic groups and conditions because of its short format (11-items) and ability to detect pain in five domains - intensity, interference, relief, quality, and perception of causes (Poquet & Lin, 2016). The studies reviewed typically focused on the domains of *pain severity* and *interference with activities* (Amspoker et al., 2021; Porter et al., 2021; Yeager et al., 2022), which are also similar to the suggested minimum observational assessment in dementia of *pain intensity* and *presence* (Achterberg et al., 2020). In dementia, at least 20 available tools are available in English which have more commonly been implemented in long-term care settings with varied reported reliability and validity. It is worth noting that even with inconsistent implementation and findings, the overall management of pain does improve with assessment (Achterberg et al., 2020).

Available pain assessments such as the
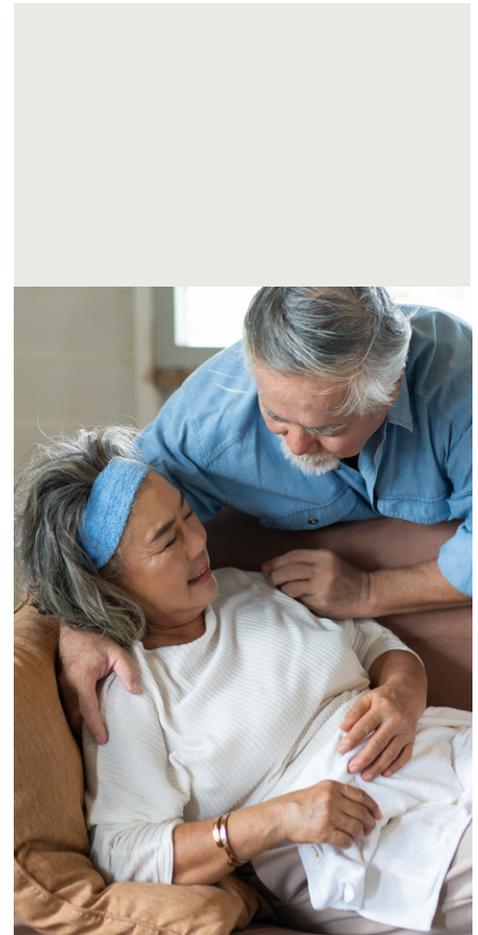
Almost 70% of caregivers assist with pain management or managing discomfort, one of the most stressful tasks caregivers assist with.

BPI involve minimal time to complete in efforts to ease respondent burden and have been included as components of interventions, but caregiver preparation is either not the intention, or pain is not the primary focus of intervention (Amspoker et al., 2021; Ferrell, 2019; Porter et al., 2021; Yeager et al., 2022). With some exceptions, including knowledge of where/how to access for personal use, assessment tools are unavailable to caregivers unless caregivers themselves are part of a study that incorporates such tools. For example, in a review comparing the effectiveness of various common pain assessment scales – McGinnis Pain Scale, Visual Analog Scale, and Numeric Rating Scale - (Hawker et al., 2011), while all measures require minimal time to complete and are free, no mention is made regarding caregiver access or administration. Further, the placement of articles detailing tools and their associated links in academic journals creates a barrier of access to caregivers who may instead use public websites, trusted organizations, or social networks to locate resources.

Smart-health technologies offer promise in terms of monitoring and capturing pain as well as variables that might influence pain, in a way that is useful to caregivers and maintains privacy concerns (LeBaron et al., 2020; Mayahara et al., 2019). According to Mayahara et al., (2019), barriers to pain management such as fatalism (belief that pain cannot be controlled) and communication challenges have emerged in other literature, but not in their study; which may be related in part to participants self-report of comfort and ease with technology. Further, additional challenges/concerns from caregivers that support the incorporation of technology include the unpredictability of pain, the impact on daily life, and concerns regarding medications (LeBaron et al., 2020). Overall, not only do caregivers appear to be interested in innovative

modalities for monitoring pain, but consistent with prior work, caregiver instruction in various formats would be useful (Reinhard et al., 2019). At this time, however, the two feasibility studies in this review are not yet widely available to caregivers.

Without question, the perspective of the person experiencing pain is the most reliable source of pain identification. However, depending on the chronic condition and the pain management strategy needed, this will vary (Achterberg et al., 2020; Chi et al., 2020). When self-report is not available, due to an inability to verbalize pain or cognitive impairment, the family caregiver is the next best option. Caregivers are able to identify a variety of patient cues to assess and communicate with other members of the health care team on behalf of their family member (LeBaron et al., 2019). Yet, one important consideration is caregiver/patient congruence. In one study examining congruence within caregiving dyads, caregivers either overestimated pain severity and interference in comparison to patients, or underestimated pain severity and interference in comparison to patients (Yeager et al., 2022). Conversely, congruence was found for pain severity between dyads, but person's living with dementia, in comparison to caregivers, were at risk for underreporting *interference with activities* over time due to the increased cognitive difficulty (Amspoker et al., 2021).

However, in spite of their expertise at identifying cues such as physical (facial, body movement, vocalizations)

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and social, pain is distressing to caregivers for a variety of reasons, not the least of which is watching a family member suffer (Achterberg et al., 2020; LeBaron et al., 2020). Yet, numerous fears are also associated with assessing and managing pain. Specifically, keeping up with or tracking medications, making mistakes, side effects, addiction to medication, and medication tolerance/ineffectiveness are the most common (Ferrell, 2019; LeBaron et al., 2020; Mayahara et al., 2019; Porter et al., 2021), which is consistent with other work (Reinhard et al., 2019). Studies discussed the incorporation of caregiver self-efficacy as part of training and education to build caregiver confidence not only to decrease fear, but also to identify and distinguish pain from other symptoms through increased pain management knowledge, as well as selecting non-pharmacological or pharmacological interventions as appropriate (Chi et al., 2020; Mayahara et al., 2019; Porter et al., 2021). Caregiver overconfidence has come up where education or training are also needed to help reduce potential for mistakes (such as not administering a needed medication), or reluctance to implement a new regimen (Mayahara et al., 2019).

Conclusion

Available tools for pain assessment have been used for decades in a variety of clinical, research, and community settings to measure pain across varied conditions, without implications or accessibility for caregiver usage. The complex nature of pain management strategies across conditions necessitates accessible and simple tools, as well as education and training for family caregivers to adequately assess and support family members. Further, including the family member in collaboration with interdisciplinary members of the health care team is a critical component to pain assessment that cannot be understated.
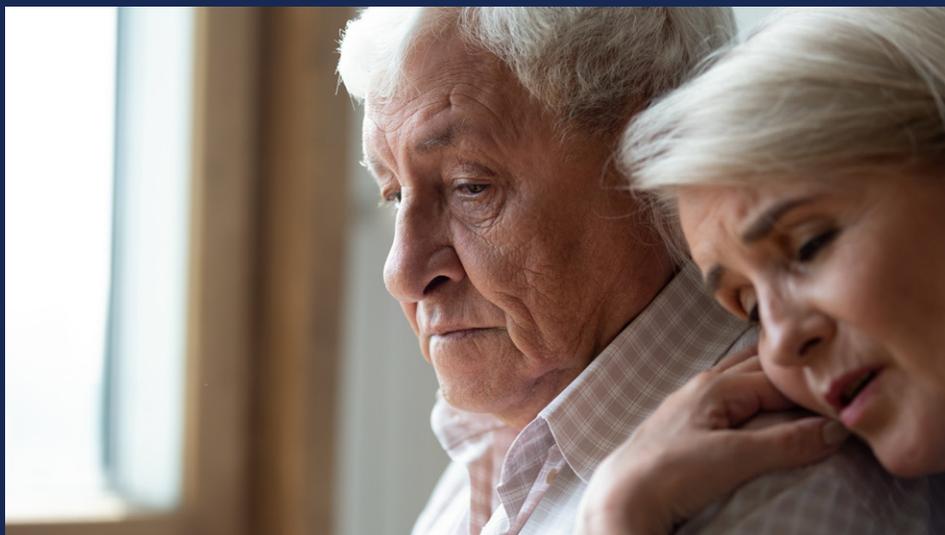
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In spite of their expertise at identifying cues such as physical (facial, body movement, vocalizations) and social, pain is distressing to caregivers for a variety of reasons, not the least of which is watching a family member suffer.

Acknowledgements

AUTHOR

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Dr. Fawn Cothran is the Hunt Research Director at the National Alliance for Caregiving. She is a nurse scientist, and a board-certified gerontological clinical nurse specialist. Prior to joining the National Alliance for Caregiving, Dr. Cothran was a faculty member with the Family Caregiving Institute in the Betty Irene Moore School of Nursing, University of California, Davis and Rush University, College of Nursing in Chicago, IL. She brings 15+ years of experience in dementia family caregiving research and related activities where her work has focused on health equity and the health of African American dementia family caregivers, including most recently caregiving stress and resilience. Dr. Cothran will help elevate national family caregiving research by designing and managing NAC research initiatives, including Caregiving in the US 2025.