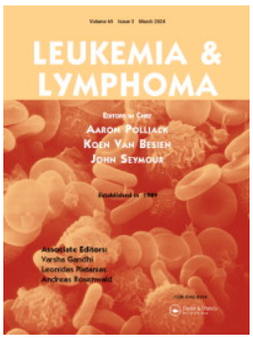
The psychological needs of adolescents and young adults with a diagnosis of myeloproliferative neoplasms: a systematic scoping review of the literature



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LETTER TO THE EDITOR

The psychological needs of adolescents and young adults with a diagnosis of myeloproliferative neoplasms: a systematic scoping review of the literature

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With an average age of onset in the sixth decade, myeloproliferative neoplasms (MPN) are classified as rare. While clinical manifestations vary by subtype, high symptom burden and reduced quality of life are frequently reported [1], with fatigue affecting up to 95% of people with an MPN [1–3], and often co-existing with mood related symptoms [2]. In addition, anxiety and depression are also common [1,4].

Around 10–20% of patients with MPN are adolescent and young adults (AYA) and are considered a growing subpopulation [5]. Indeed, it is increasingly recognized that the AYA oncology population are particularly vulnerable [6] due to their unique and complex developmental stage [7]. While the MPN AYA group generally reports a similar symptom burden to the adults with MPN [8], very little is known about the psychological impact and management of AYA with MPN. Understanding psychosocial issues patients with MPN face are critical given the demands of cancer, and its treatment is often directly counter to the developmental needs of the age group [9,10]. As such, the extrapolation of outcomes from the older population of individuals with MPN to this younger AYA population may not be helpful [11].

Thus, our systematic scoping review aimed to synthesize the research in the MPN AYA age group (16–39 years) to determine the psychological impact and relevance of psychological support for this group. The protocol for this study was developed using the PRISMA-Scoping Reviews Checklist [12] and was registered in Open Science Framework on 26 August 2022 (https://osf.io/7rpy5/). A systematic search of key databases (Psych Info, Medline, CINAHL, Embase, Web of Science, Scopus, and the Cochrane Library) and gray literature servers (MedRxiv, BioRxiv, Europe PMC, OSF Preprints; oatd.org) of all quantitative and qualitative articles published in English (2002 to 12 February 2023) was undertaken. The key search terms used for all searches were: 'MPN' and: psychological impact; psychological difficulty; emotional impact; anxiety; depression; psychological screening; rehabilitation; AYA; psychosocial; and quality of life. We searched the reference lists of all included studies and systematic reviews identified in the search for other relevant sources. Searches identified 5563 articles (Figure 1).

The de-duplicated bibliographic database citations were uploaded into Rayyan and titles and abstracts were independently screened by two reviewers (TH and HLR), and disagreements (n = 1) were resolved through discussion with a third reviewer (DGF). No studies specifically reported data confined to the AYA age cohort. Twenty-seven articles were identified as potentially containing additional data due to age-ranges reported. Following requests for access to raw data, five data sources [3,4,13–15] were included in the final synthesis (see Table 1 for characteristics of included studies).

We present findings relating to fatigue, emotional impact, developmental stage impacts, distress screening tools, and psychological interventions.

Commensurate with the literature [1,2], data retrieved suggested fatigue was challenging for AYA and very few AYA reported having the confidence to manage fatigue related distress [14]. Fatigue was cited as problematic by the AYA participants, both in terms of the impact of fatigue on their life and the need to adjust their work to take account of the fatigue [14]. How fatigue was handled by medical professionals was reported to be unhelpful [3] and to have an impact on under reporting of symptoms [3]. AYA were uncertain as to whether fatigue was due to lifestyle or MPN related factors [3,14]. Hand in hand with fatigue, sleep difficulties were also identified [15]. While it was difficult to ascertain whether the problems with sleep were mood related, tiredness, fatigue, and emotional impact were seen to be closely related.

In terms of psychosocial sequelae, our review indicated that around 20–30% of the AYA population with

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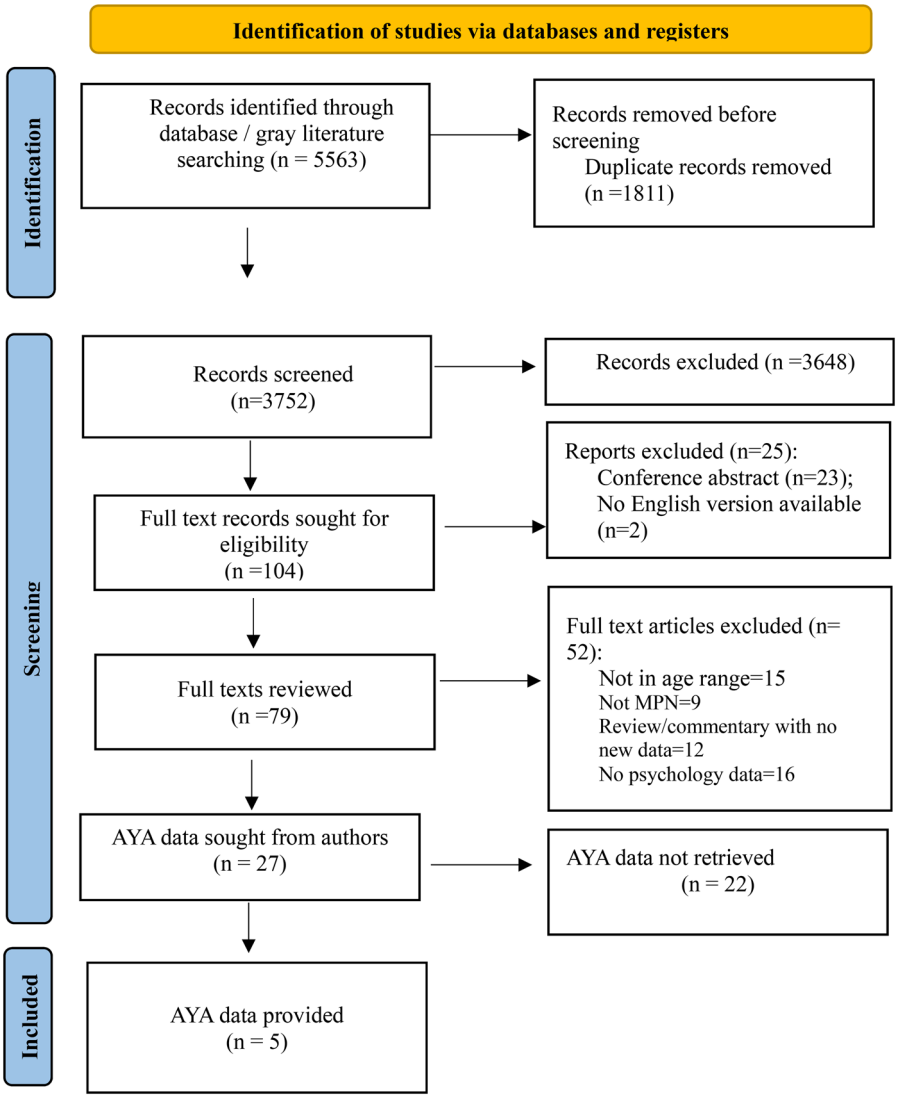

Figure 1. PRISMA 2020 flow diagram of search results.

MPN experienced levels of psychological distress that would warrant further assessment/intervention [4,14]. This figure is in line with hematological cancers generally [16], and MPN diagnoses specifically [17] and is concordant with the finding that younger people with MPN had a higher incidence of both anxiety and depression than middle age or older people with MPN [17]. Importantly, a sub-analysis of nine AYA responses [14] to the Patient Health Questionnaire-4, demonstrated AYA scored across all four severity subscales, indicating a potential need for universal psychosocial screening of the AYA population.

Findings identified relevant to the developmental stage of the AYA with MPN indicated uncertainty around the future in terms of health status [3] and impacts on career [14]. AYA with MPN reported differences between themselves and peers without MPN citing distress in relation to not being able to do as much as their contemporaries [3]. In line with this, almost 50% reported reducing their hours at work or changing their job due to MPN [14].

We identified three psychometric assessment tools across two studies [4,14], used to assess psychological distress (HADS, DT and problem list and PHQ-4) and one measure of quality of life (FACIT-Fatigue) containing a measure of EWB. With lower scores indicating poorer function, we note the median score of 14 on the EWB scale is below that of population mean norms (19.9), and cancer population norms (18.7) [18], and as such highlight the consideration of specific AYA needs. Of the tools utilized, the HADS [19] is probably the most well-established measure and has been used across many conditions including cancer [20], AYA populations [21] and MPN [4,17] as a measure of psychological distress. The financial costs and licensing associated with using the HADS may rule out the utility of this instrument for routine use in many institutions. Given the specific needs of the AYA cancer group [21,22], it is important that appropriate measures are utilized when screening for distress. It is noted that validation work on the AYA modified version of the DT and problem check list [22] has begun in an international AYA population [21].

Table 1. Characteristics of studies included in this systematic scoping review.

Study authors	Year	Country	Design	Overall aim	Sample size	Measures of quality of life and psychological distress	Main findings relevant to review question
Bradford (PhD thesis)	2020	Australia	Mixed method Online survey and qualitative (semi-structured interview and focus groups) TA	To gain insight into the lived experience of fatigue in MPN.	Online survey, n = 82 (AYA, n[b] = 11 ; 9 female) Qualitative, n = 23 (AYA n = 1; female; reported in Bradford et al. [3])	FACIT-F (including EWB subscale) PH4-4	Over 50% had low confidence in managing emotions around fatigue; one third fell in moderate to severe range of psychological distress on PHQ-4.
Bradford et al. [3][a]	2023	Australia	Qualitative (semi-structured interview and focus groups) TA	To better understand the lived experience of fatigue associated with MPN	Qualitative, n = 23 AYA n = 1	–	Emotional impact of living with MPN; Uncertainty about the future; Impact on relationships; Impact on activities; Poverty of appropriate support.
Huberty et al. [15]	2019	U.S.A.	Qualitative Semi-structured interview TA	To explore individuals with MPN experiences of using a mobile phone app to manage fatigue.	n = 48 (mean 59 years, SD 10 years) n[c] = 2 (32 years, 37 years)	–	Positive perception of using mobile phone app and helpful in terms of 'stress management', 'sleep', and 'distraction'. Intention to continue to use mobile phone app.
McFarland et al. [4]	2016	U.S.A.	Cross-sectional survey	To examine the prevalence of psychological distress and its relationship with clinical and demographic variables in patients with MPN.	n = 117, mean age 57.7 years (SD 14.8) n[d] = 14 (20–38 years)	HADS DT and PL	AYA with MPN experienced clinically relevant levels of psychological distress which warranted psychological attention.
McFarland et al. [13]	2017	U.S.A.	Cross-sectional survey	Preferences for accepting treatment for anxiety and depression in patients with MPN.	As per McFarland et al. [4] n = 14	–	No AYA with MPN were taking antidepressants. 50% were happy to be treated with an antidepressant. The majority would be happy for their oncologist to prescribe an antidepressant.

TA: thematic analysis; HADS: Hospital Anxiety and Depression Scale; DT: distress thermometer and problem list; FACIT-F: Functional Assessment of Chronic Illness Therapy-Fatigue; EWB: emotional well-being; PHQ-4: Patient Health Questionnaire-4.
[a]Article derived from Bradford [14] PhD thesis.
[b]Authors provided survey responses for n = 11 participants in 18–39 years age group.
[c]Authors provided qualitative transcripts for n = 2 AYA in 18–39 years age group.
[d]Authors provided raw data to enable sub-analysis for n = 14 AYA in 18–39 years age group.

Our review has identified significant gaps in the literature relating to psychosocial outcomes and interventions for AYA diagnosed with MPN. The only available data sourced on psychosocial interventions for MPN [15] reported qualitative data from two AYA wherein a digital mindfulness application for fatigue was considered acceptable and convenient for participants. Both AYA participants reported liking the ease of the smart phone apps and the benefits of the app were expressed not in terms of sleep quality but related to relaxation and distraction [15]. While we are not able to comment further on the characteristics of AYA patients with MPN who might benefit from psychological interventions, there may be value in further developing and testing digital health interventions to support AYA with psychological concerns [15,23].

While available raw data indicated that none of the AYA participants were taking antidepressants, half (n = 7) expressed a willingness to accept an antidepressant [13]

and were happy with their hematologist/oncologist prescribing the antidepressant. Five individuals expressed a preference to be treated by a mental health professional rather than their hematologist/oncologist. The importance of support from family was also demonstrated in qualitative data [3,14] where a majority of the AYA group reported receiving little or no support from their family indicating possible unmet support needs for AYA with MPN [14].

In terms of limitations, the data obtained relating to AYA with MPN represented a low number of participants which limits the generalizability of the findings of this review. Nonetheless, the results of the sub analysis were commensurate with other studies in the AYA oncology group. We limited data to that provided in the English language, and recognize the potential cultural biases in data provided in this respect. However, no studies were excluded at full text review on this basis. As we set out to undertake a scoping review of the literature, no rating of the quality of articles was undertaken.

There are a number of key implications arising from the review. First, ongoing international collaboration between MPN researchers, practitioners and organizations would help to capture optimal sample sizes and further data of interest, while also potentially addressing current cultural bias in existing data. Second, there remains a paucity of access to data related to the AYA population and we would encourage researchers to examine this sub-group of AYA in their existent data sets and utilize FAIR (Findable, Accessible, Interoperable, Reusable) guidelines [24] in terms of data stewardship. Third, it would be prudent for researchers to publish future research protocols. Such good practice initiatives should help to develop appropriate hypotheses and develop understanding while avoiding unnecessary repetition and overburdening of research participants. Finally, while Public and Patient Involvement (PPI) is considered best practice [25], we note that none of the data arising from studies included within this systematic scoping review reported evidence of PPI. Given the positive impacts of PPI [26], instilling a culture of PPI with investigators conducting research with AYA patients with MPN would help to improve the quality and relevance of research.

In summary, this systematic scoping review found no research specifically related to the psychological needs of AYA with MPN. Future research must utilize best practice guidelines in using methodologically appropriate and transparently reported studies to explore the specific psychological needs of the AYA cohort with MPN. It is critical that we understand the prevalence of distress in this group of MPN patients so that we can appropriately assess, identify, monitor, formulate, and provide appropriate care and treatment for such individuals.

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Author contributions

TH: conceptualization, investigation, curation of data and writing – original draft. DGF: visualization, formal analysis, writing – review and editing. CK: visualization, writing – review, and editing. HLR: conceptualization, visualization, formal analysis, curation of data, writing – review and editing, supervision.

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References

[1] Harrison CN, Koschmieder S, Foltz L, et al. The impact of myeloproliferative neoplasms (MPNs) on patient quality of life and productivity: results from the International MPN Landmark Survey. Ann Hematol. 2017;96(10):1653–1665. doi:10.1007/s00277-017-3082-y
[2] Scherber RM, Kosiorek HE, Senyak Z, et al. Comprehensively understanding fatigue in patients with myeloproliferative neoplasms. Cancer. 2016;122(3):477–485. doi:10.1002/cncr.29753
[3] Bradford A, Young K, Whitechurch A, et al. Disabled, invisible and dismissed—the lived experience of fatigue in people with myeloproliferative neoplasms. Cancer Rep. 2023;6(1):e1655.
[4] McFarland DC, Polizzi H, Mascarenhas J, et al. Psychological symptoms among patients with BCR-ABL-negative myeloproliferative neoplasms. J Natl Compr Canc Netw. 2016;14(12):1563–1570. doi:10.6004/jnccn.2016.0168
[5] Roaldsnes C, Holst R, Frederiksen H, et al. Myeloproliferative neoplasms: trends in incidence, prevalence and survival in Norway. Eur J Haematol. 2017;98(1):85–93. doi:10.1111/ejh.12788
[6] Thomas DM, Albritton KH, Ferrari A. Adolescent and young adult oncology: an emerging field. J Clin Oncol. 2010;28(32):4781–4782. doi:10.1200/JCO.2010.30.5128
[7] Ferrari A, Stark D, Peccatori FA, et al. Adolescents and young adults (AYA) with cancer: a position paper from the AYA Working Group of the European Society for Medical Oncology (ESMO) and the European Society for Paediatric Oncology (SIOPE). ESMO Open. 2021;6(2):100096. doi:10.1016/j.esmoop.2021.100096
[8] Ianotto JC, Curto-Garcia N, Lauermanova M, et al. Characteristics and outcomes of patients with essential thrombocythemia or polycythemia vera diagnosed before 20 years of age: a systematic review. Haematologica. 2019;104(8):1580–1588. doi:10.3324/haematol.2018.200832
[9] Sodergren SC, Husson O, Robinson J, et al. Systematic review of the health-related quality of life issues facing ad-

olescents and young adults with cancer. Qual Life Res. 2017;26(7):1659–1672. doi:10.1007/s11136-017-1520-x
[10] Docherty SL, Kayle M, Maslow GR, et al. The adolescent and young adult with cancer: a developmental life course perspective. Semin Oncol Nurs. 2015;31(3):186–196. doi:10.1016/j.soncn.2015.05.006
[11] Janssen SHM, van der Graaf WTA, van der Meer DJ, et al. Adolescent and young adult (AYA) cancer survivorship practices: an overview. Cancers. 2021;13(19):4847. doi:10.3390/cancers13194847
[12] Tricco AC, Lillie E, Zarin W, et al. PRISMA extension for scoping reviews (PRISMA-ScR): checklist and explanation. Ann Intern Med. 2018;169(7):467–473. doi:10.7326/M18-0850
[13] McFarland DC, Shen MJ, Polizzi H, et al. Preferences of patients with myeloproliferative neoplasms for accepting anxiety or depression treatment. Psychosomatics. 2017;58(1):56–63. doi:10.1016/j.psym.2016.08.006
[14] Bradford A. Living with MPN fatigue [thesis]. Melbourne, Australia: University of Melbourne; 2020.
[15] Huberty J, Eckert R, Larkey L, et al. Experiences of using a consumer-based mobile meditation app to improve fatigue in myeloproliferative patients: qualitative study. JMIR Cancer. 2019;5(2):e14292. doi:10.2196/14292
[16] Clinton-McHarg T, Carey M, Sanson-Fisher R, et al. Anxiety and depression among haematological cancer patients attending treatment centres: prevalence and predictors. J Affect Disord. 2014;165:176–181. doi:10.1016/j.jad.2014.04.072
[17] Brochmann N, Flachs EM, Christensen AI, et al. Anxiety and depression in patients with Philadelphia-negative myeloproliferative neoplasms: a nationwide population-based survey in Denmark. Clin Epidemiol. 2019;11:23–33. doi:10.2147/CLEP.S162688
[18] Brucker PS, Yost K, Cashy J, et al. General population and cancer patient norms for the Functional Assessment of Cancer Therapy-General (FACT-G). Eval Health Prof. 2005;28(2):192–211. doi:10.1177/0163278705275341
[19] Zigmond AS, Snaith RP. The Hospital Anxiety and Depression Scale. Acta Psychiatr Scand. 1983;67(6):361–370. doi:10.1111/j.1600-0447.1983.tb09716.x
[20] Annunziata MA, Muzzatti B, Bidoli E, et al. Hospital Anxiety and Depression Scale (HADS) accuracy in cancer patients. Support Care Cancer. 2020;28(8):3921–3926. doi:10.1007/s00520-019-05244-8
[21] Patterson P, D'Agostino NM, McDonald FEJ, et al. Screening for distress and needs: findings from a multinational validation of the adolescent and young adult psycho-oncology screening tool with newly diagnosed patients. Psychooncology. 2021;30(11):1849–1858. doi:10.1002/pon.5757
[22] Palmer S, Patterson P, Thompson K. A national approach to improving adolescent and young adult (AYA) oncology psychosocial care: the development of AYA-specific psychosocial assessment and care tools. Palliat Support Care. 2014;12(3):183–188. doi:10.1017/S1478951512001083
[23] Shah A, Hussain-Shamsy N, Strudwick G, et al. Digital health interventions for depression and anxiety among people with chronic conditions: scoping review. J Med Internet Res. 2022;24(9):e38030. doi:10.2196/38030
[24] Wilkinson MD, Dumontier M, Aalbersberg IJ, et al. The FAIR guiding principles for scientific data management and stewardship. Sci Data. 2016;3(1):160018. doi:10.1038/sdata.2016.18
[25] Absolom K, Holch P, Woroncow B, et al. Beyond lip service and box ticking: how effective patient engagement is integral to the development and delivery of patient-reported outcomes. Qual Life Res. 2015;24(5):1077–1085. doi:10.1007/s11136-014-0909-z
[26] Crocker JC, Ricci-Cabello I, Parker A, et al. Impact of patient and public involvement on enrolment and retention in clinical trials: systematic review and meta-analysis. BMJ. 2018;363:k4738. doi:10.1136/bmj.k4738