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ORIGINAL RESEARCH

Knowledge, Attitudes, and Practices Towards Waldenström's Macroglobulinemia Among Patients and Their Family Members

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Objective: This study aimed to investigate the knowledge, attitude, and practice (KAP) regarding Waldenström's Macroglobulinemia (WM) among patients and their family members, and to compare differences between these two groups.

Methods: This cross-sectional survey was conducted in October 27, 2023 to Nov 27, 2023 at a tertiary hospital in Zhejiang Province, targeting WM patients and their family members. Demographic characteristics and KAP scores were collected through self-administered questionnaires.

Results: A total of 220 valid questionnaires were analyzed, with 98 (44.55%) from patients. The overall mean knowledge, attitude, and practice scores were 10.38±4.07 (possible range: 0–16), 15.78±2.34 (possible range: 5–25), and 23.19±3.31 (possible range: 6–30), respectively. Patients had significantly higher knowledge scores than family members (11.13±4.28 vs 9.78±3.79, P = 0.004), while no significant differences were found in attitude (15.78±2.27 vs 15.77±2.40, P = 0.889) or practice scores (23.59±2.94 vs 22.87 ±3.56, P = 0.134). Correlation analysis revealed a positive correlation between knowledge and attitude (r = 0.1879, P = 0.0052) and practice (r = 0.1670, P = 0.0132). However, the correlation between attitudes and practices was not significant. Structural equation modeling (SEM) results showed no direct effect between knowledge and attitude (P = 0.312) or knowledge and practice (P = 0.067). In contrast, attitude directly and negatively affected practice (β = −0.10, P = 0.036).

Conclusion: WM patients and their family members demonstrated moderate levels of knowledge, attitudes, and practices toward WM. To enhance clinical outcomes, interventions should focus on improving attitudes, given their direct and negative impact on practices.

Keywords: knowledge, attitude, practices, Waldenström's macroglobulinemia, family members

Introduction

Waldenström's macroglobulinemia (WM), first described by J. Waldenström in 1944, accounts for approximately 2% of all hematologic malignancies.[1] This rare B-cell lymphoma, characterized by bone marrow infiltration of lymphoplasmacytic cells leading to the secretion of IgM proteins, falls within the category of indolent non-Hodgkin lymphomas (NHLs), with an incidence of merely 0.3 per 100,000 person-years.[2–5] Patients with WM often present with a spectrum of clinical manifestations, encompassing fatigue, discomfort, fever, weight loss, and, in certain instances, symptoms related to hyperviscosity.[6,7] The disease's gradual onset, combined with its incurable nature, significantly impacts patients' quality of life, necessitating sustained management. Beyond individual health implications, the scarcity of awareness surrounding WM on a societal level poses a potential challenge, potentially resulting in delayed diagnosis and treatment commencement. As such, the study of WM assumes paramount importance in the realm of public health.

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The Knowledge, Attitude, and Practice (KAP) framework plays a crucial role in shaping health-related behaviors.[8] It is often employed alongside the KAP questionnaire to comprehensively gauge the KAP of the target population within the healthcare domain, as well as to assess the demand and level of acceptance of relevant content.[9] This model, integral to health literacy, is underpinned by the fundamental premise that knowledge exerts a positive influence on attitudes, and these attitudes, in turn, shape individual practices.[10]

Notably, WM is frequently diagnosed in the later stages of life, typically around the median age of 73 years, adding a considerable burden of medical and nursing stress on both patients and their families.[11] Although existing research indicates relatively low rates of adverse events and treatment discontinuation (with a 10% serious adverse events and a 6.4% discontinuation rate), our understanding of the challenges faced by patients and their families in coping with this rare disease remains limited.[12] Notably, patients and families contribute significantly to the overall well-being of those affected by WM by playing a pivotal role in adhering to treatment plans, attending regular follow-up appointments, and implementing essential lifestyle modifications. Therefore, the imperative to conduct a KAP study among WM patients and their families is underscored, as it promises to unveil crucial insights that can enhance communication, inform treatment strategies, and ultimately elevate the standard of care for this specific patient community.

Therefore, this study aimed to investigate the KAP towards WM among patients and their family members, and to explore differences in KAP scores between the two groups.

Methods

Study Design and Participants

This cross-sectional study was conducted in October 2023 at a tertiary hospital in Zhejiang Province, China. The participants included individuals diagnosed with WM and their family members. The inclusion criteria were: 1) aged > 18 years old; 2) Patients or their family members registered with the Chinese WM/LPL Patient Association. The study received ethical approval from the Clinical Research Ethics Committee of the First Affiliated Hospital of Zhejiang University (IIT20230387B) and informed consent was obtained from all participants.

Questionnaire Introduction

The questionnaire was developed based on a review of relevant literature and the Chinese guideline for diagnosis and treatment of lymphoplasmacytic lymphoma/Waldenström macroglobulinemia (2022). Initial items were drafted by the research team and subsequently reviewed by two hematology professors with over 10 years of clinical experience. Based on their feedback, the items were revised to improve clarity and clinical relevance. Additionally, one item regarding the slow onset of treatment and the importance of not changing treatment plans without clear evidence of disease progression was added to the knowledge section.

A pilot test was conducted among 60 participants (WM patients and family members). Participants were encouraged to report any unclear or ambiguous items. Minor revisions to wording and formatting were made to improve item clarity and readability. Internal consistency reliability was assessed using Cronbach's α, yielding an acceptable value of 0.776.

The final questionnaire consisted of four sections: demographic characteristics, knowledge, attitudes, and practices (KAP). The knowledge section included eight items scored as 2 ("well-known"), 1 ("heard of"), or 0 ("unknown"), with a total score range of 0–16. The attitude section comprised 11 items measured on a five-point Likert scale; items A1, A2, and A4 were reverse-coded, while A3 and A5 were positively coded, yielding a total score range of 5–25. The practice section included six items measured on a five-point Likert scale ranging from 5 ("always") to 1 ("never"), with a total possible score of 6–30.

The questionnaire was distributed online using the "Wenjuanxing" survey platform. A QR code and access link were shared through the official channel of the China WM/LPL Patient Association to ensure broad national reach. Patients and family members accessed and completed the survey voluntarily. Family members of WM patients were required to complete the knowledge and attitude dimensions based on their own experiences, while the practice dimension was completed based on the actions performed by the WM patients.

Overall knowledge, attitude, and practice scores were classified using a modified Bloom's criteria cutoff point: scores between 80–100% were categorized as good, 60–79% as moderate, and less than 60% as poor knowledge, negative attitude, and inappropriate practice, respectively.[13]

Statistical Analysis

SPSS 26.0 (IBM, Armonk, NY, USA) and STATA 14 (Stata Corporation, College Station, TX, USA) were used for statistical analysis. Continuous variables were described using mean ± standard deviation (SD), and compared by analysis of variance (ANOVA) for those conforming to a normal distribution, and Kruskal–Wallis *H*-test for those conforming to a skewed distribution. Categorical variables were presented as n (%). The correlation among KAP scores was assessed using Spearman analysis, and the interactions among KAP were explored through structural equation modeling (SEM). Additionally, a subgroup analysis was conducted to compare individual KAP item scores between participants who were employed versus those who were not, to explore potential influences of socioeconomic status. Two-sided $P<0.05$ were considered statistically significant in this study.

Results

In this study, a total of 229 responses were collected, and 220 valid questionnaires were obtained after one response with completion time less than 180 seconds, one respondent below 18 years of age, and seven responses containing logical errors were excluded. Among them, 98 (44.55%) were families of the patients and 133 (60.45%) were males, with a mean age of 51.79±14.08 years. The mean duration of diagnosis of the patients was 51.34±32.90 months, 108 (49.09%) were undergoing BTK inhibitor-based treatment, 160 (72.73%) had not experienced relapse. This high proportion of BTKi usage among non-relapsed patients may be attributed to the increasing adoption of BTK inhibitors as first-line therapies in real-world practice, especially among elderly patients or those with comorbid conditions, due to their favorable safety profile and oral administration convenience. Additionally, 122 (55.45%) had no other underlying disease, 138 (62.73%) underwent their first visit due to physical symptoms, 147 (66.82%) attended in the hematology department, 129 (58.64%) experienced not suspected of having WM or misdiagnosed.

The mean knowledge, attitude, and practice scores were 10.38±4.07, 15.78±2.34, and 23.19±3.31, separately. Analyses of demographic characteristics showed that patients tended to have higher knowledge scores than family members (11.13±4.28 vs 9.78±3.79, $P = 0.004$), while no significant differences were found in attitude (15.78±2.27 vs 15.77±2.40, $P = 0.889$) or practice scores (23.59±2.94 vs 22.87±3.56, $P = 0.134$). Those with different education were more likely to have different levels of knowledge ($P = 0.014$). Differences in work status before developing WM were also more likely to show differences in knowledge, attitudes, and practices ($P = 0.042$, $P = 0.018$, $P = 0.027$, respectively). Moreover, participants with different current treatments ($P = 0.023$ and $P = 0.023$) and different reasons for initial visits ($P = 0.033$ and $P = 0.034$) were more likely to have different knowledge and practices (Table 1).

The response for knowledge dimension shows that the two questions with the highest number of participants choosing the "Well-known" option were

> WM is currently incurable, and most patients cannot achieve complete remission. The treatment goal is symptom relief and reducing the risk of organ damage. (K7) with 52.73%

And

> Genetic testing (such as MYD88 and CXCR4 mutations) is necessary for WM, and treatment decisions should be guided by the patient's genetic mutation status. (K6) with 49.55%

Oppositely, The two questions with the highest number of participants choosing the "Unknown" option were "Elevated IgM levels alone are not an indication to start treatment." (K4) with 14.09% and "WM is a rare indolent lymphoma that primarily affects the elderly, with a median survival of 8 years." (K1) with 13.64% (Supplemental Table 1).

The attitude dimension shows that 35.91% agree that the disease has caused them unbearable suffering (A1), but 52.27% are glad about the possibility of achieving objective remission or even complete remission through long-term treatment (A3). On the other hand, 42.73% were neutral about the adverse effects of drugs that make it difficult to adhere

Table 1 Basic Characteristics and KAP Scores

Variable	Category	n (%)	Knowledge		Attitude		Practice	
			Mean ± SD	P	Mean ± SD	P	Mean ± SD	P
Total Score			10.38 ± 4.07		15.78 ± 2.34		23.19 ±3.31	
Identity	Patient	98 (44.55)	11.13 ± 4.28	0.004	15.78 ± 2.27	0.889	23.59 ± 2.94	0.134
	Family Member	122 (55.45)	9.78 ± 3.79		15.77 ± 2.40		22.87 ± 3.56	
Gender	Male	133 (60.45)	10.67 ± 4.24	0.117	15.63 ± 2.44	0.140	23.28 ± 3.53	0.500
	Female	87 (39.55)	9.94 ± 3.77		16.01 ± 2.17		23.05 ± 2.96	
Residence	Urban	138 (62.73)	10.73 ± 3.96	0.084	15.96 ± 2.27	0.172	23.35 ± 3.08	0.424
	Rural	48 (21.82)	9.17 ± 4.23		15.64 ± 2.42		23.31 ± 3.69	
	Suburban	34 (15.45)	10.67 ± 4.05		15.23 ± 2.45		22.38 ± 3.64	
Education	≤ Junior High	56 (25.45)	9.91 ± 4.17	0.014	15.80 ± 2.47	0.568	23.60 ± 3.44	0.298
	High/Vocational School	30 (13.64)	8.83 ± 4.82		15.36 ± 2.48		21.93 ± 3.48	
	College	42 (19.09)	9.83 ± 3.53		15.71 ± 2.50		23.45 ± 3.36	
	≥ Bachelor's	92 (41.82)	11.43 ± 3.75		15.93 ± 2.15		23.23 ± 3.10	
Employment Before Diagnosis	Full-time	67 (30.45)	11.52 ± 3.79	0.042	16.41 ± 2.30	0.018	23.28 ± 3.05	0.027
	Self-employed	72 (32.73)	9.68 ± 3.91		15.72 ± 2.44		22.52 ± 3.65	
	Retired	68 (30.91)	10.19 ± 4.04		15.42 ± 2.28		23.50 ± 3.30	
	Homemaker	13 (5.91)	9.46 ± 5.44		14.69 ± 1.43		24.84 ± 1.72	
Current Employment	Full-time	44 (20.00)	11.27 ± 3.49	0.139	16.43 ± 2.42	0.070	23.25 ± 3.36	0.269
	Self-employed	33 (15.00)	10.12 ± 4.62		16.27 ± 2.64		22.96 ± 4.02	
	Retired	81 (36.82)	10.40 ± 4.21		15.70 ± 2.37		23.64 ± 2.94	
	Homemaker	26 (11.82)	10.80 ± 4.02		15.30 ± 2.03		23.57 ± 2.48	
	Unable to work	36 (16.36)	9.19 ± 3.78		15.05 ± 1.83		22.05 ± 3.72	
Same City as Hospital	Yes	138 (62.73)	10.39 ± 4.18	0.885	15.96 ± 2.42	0.193	23.15 ± 3.40	0.989
	No	82 (37.27)	10.36 ± 3.89		15.47 ± 2.17		23.25 ± 3.18	
Monthly Income (¥)	<2000	19 (8.64)	8.95 ± 4.03	0.885	14.42 ± 2.38	0.193	23.52 ± 3.96	0.989
	2000–5000	77 (35.00)	9.99 ± 4.18		15.37 ± 2.10		22.81 ± 3.28	
	5000–10,000	63 (28.64)	10.95 ± 3.85		16.30 ± 2.54		23.14 ± 3.67	
	10,000–20,000	39 (17.73)	10.38 ± 4.16		15.79 ± 2.05		23.87 ± 2.67	
	>20,000	22 (10.00)	11.40 ± 3.94		16.86 ± 2.27		23.18 ± 2.80	
Marital Status	Single/Divorced/Widowed	29 (13.18)	10.20 ± 3.99	0.755	15.06 ± 2.25	0.135	22.62 ± 3.56	0.185
	Married	191 (86.82)	10.41 ± 4.09		15.89 ± 2.34		23.28 ± 3.27	
Current Treatment	Observation	37 (16.82)	11.18 ± 3.80	0.023	15.72 ± 2.06	0.917	24.24 ± 3.25	0.023
	CD20-based	6 (2.73)	13.16 ± 4.62		16.50 ± 1.37		21.33 ± 3.61	
	Lenalidomide + Bendamustine	42 (19.09)	10.88 ± 3.90		15.92 ± 2.41		23.76 ± 3.02	
	Bortezomib	15 (6.82)	8.87 ± 3.60		15.53 ± 2.61		21.80 ± 4.61	
	BTK inhibitors	108 (49.09)	10.23 ± 4.23		15.76 ± 2.45		23.11 ± 3.17	
	CD38 antibodies	12 (5.45)	8.08 ± 2.84		15.50 ± 2.19		21.41 ± 2.46	
Relapse	No	160 (72.73)	10.22 ± 4.14	0.242	15.96 ± 2.33	0.053	23.17 ± 3.37	0.859
	Yes	60 (27.27)	10.81 ± 3.87		15.28 ± 2.30		23.25 ± 3.16	
Initial Visit Reason	Physical Symptoms	138 (62.73)	9.93 ± 3.92	0.033	15.66 ± 2.29	0.371	22.91 ± 3.44	0.034
	Check-up Abnormalities	41 (18.64)	11.68 ± 3.73		16.36 ± 2.54		24.36 ± 2.61	
	During other treatment	28 (12.73)	11.35 ± 4.65		15.78 ± 2.37		23.25 ± 3.61	
	Other	13 (5.91)	9.08 ± 4.36		15.15 ± 1.99		22.38 ± 2.53	
Misdiagnosed or Not Suspected	Yes	91 (41.36)	10.01 ± 4.34	0.369	15.70 ± 2.36	0.836	22.96 ± 3.69	0.565
	No	129 (58.64)	10.65 ± 3.85		15.83 ± 2.33		23.35 ± 3.02	

to standard treatment (A2). It is noteworthy that 41.36% were very concerned about the possibility of WM being passed on to future generations (A4). 63.18% were very interested in joining a patient group to share experiences and receive emotional support (A6) (Supplemental Table 2). Besides, 82.73% of participants were primarily perplexed about the progression of WM (A6). Following diagnosis, 71.36% demonstrated the ability to self-regulate and cope with their condition (A7). Furthermore, 57.73% reported that the doctor provided and explained multiple options during communication, allowing the patient to make an informed choice (A8). Concurrently, 75.91% expressed a desire to exercise autonomy in decision-making regarding their treatment (A9). Information was obtained through the Internet, WeChat, and other channels by 54.09% of participants (A10). In comparison with other considerations, 40.91% deemed the most crucial role to be the prolongation of life expectancy (A11) (Supplemental Table 3).

The practice dimension reveals that 43.18% consistently adhere to regular follow-ups (P1), while 71.82% consistently adhere to prescribed medication regimens. Furthermore, 47.27% frequently maintain a healthy and balanced diet and ensure sufficient sleep (P6). However, 50.91% have never received the latest influenza and pneumonia vaccinations (P5) (Supplemental Table 4).

To further explore the differences between patients and family members, additional analyses were performed to compare the detailed responses of the two populations. For the knowledge dimension questions, patients scored significantly higher than the family members on all questions except "Patients with symptomatic hyperviscosity should undergo plasmapheresis 2–3 times before systemic treatment." (K5) and "The onset of WM treatment is relatively slow. Unless there is clear evidence of disease progression, treatment regimens should not be changed frequently." (K8), showing a higher level of knowledge (Supplemental Table 5). For all attitude dimension questions, there was no significant difference in scores between patients and family members, showing similar attitudinal positivity (Supplemental Table 6). In the practice dimension, patients scored significantly higher than their families in regular follow-up appointments (P1), medication adherence (P2), and preventive hygiene measures (P4), reflecting potential discrepancies between self-reports and proxy assessments, which is consistent with existing literature on patient-proxy reporting differences (Supplemental Table 7).

Furthermore, subgroup comparisons based on employment status (employed vs unemployed) revealed significant differences in selected items across all three domains. Specifically, K5 (P=0.026), A2 (P=0.031), P3 (P=0.041), and P6 (P=0.015) showed statistically significant differences. These findings suggest that employment status, potentially reflecting socioeconomic or functional differences, may influence awareness and behavior related to WM (Supplementary Table 8).

The correlation analysis reveals that knowledge was positively correlated with attitudes (r = 0.1879, P = 0.0052) and practices (r = 0.1670, P = 0.0132), however, there was a negative correlation between attitudes and practices (r = −0.0784, P = 0.2468) (Table 2). And the SEM shows that there is no direct effect between knowledge and attitudes (P = 0.312), as well as knowledge and practices (P = 0.067). While, attitudes directly and negatively affect practices (β = −0.10, p = 0.036) (Table 3 and Supplementary Figure 1).

Table 2 Correlation Analysis

	Knowledge	Attitude	Practice
Knowledge	1		
Attitude	0.188 (P=0.005)	1	
Practice	0.167 (P=0.013)	−0.078 (P=0.247)	1

Table 3 SEM Path Analysis

			Estimate	Std. Err.	P
A <-	<–	K	0.122	0.121	0.312
P <-	<–	A	−0.10	0.048	0.036
P <-	<–	K	0.096	0.052	0.067
K1	<–	K	1		
K2	<–	K	1.016	0.091	<0.001
K3	<–	K	0.965	0.084	<0.001
K4	<–	K	1.127	0.100	<0.001
K5	<–	K	1.030	0.109	<0.001

(*Continued*)

Table 3 (Continued).

			Estimate	Std. Err.	P
K6	<–	K	0.962	0.098	<0.001
K7	<–	K	0.952	0.084	<0.001
K8	<–	K	1.012	0.094	<0.001
A1	<–	A	1		
A2	<–	A	0.983	0.207	<0.001
A3	<–	A	−0.02	0.094	0.783
A4	<–	A	0.677	0.158	<0.001
A5	<–	A	−0.17	0.076	0.024
P1	<–	P	1		
P2	<–	P	0.964	0.325	0.003
P3	<–	P	2.716	0.804	0.001
P4	<–	P	2.451	0.730	0.001
P5	<–	P	1.478	0.590	0.012
P6	<–	P	1.616	0.501	0.001

Construct validity was supported by confirmatory factor analysis (CFA), which showed acceptable model fit, with the following indices: KMO = 0.831, CMIN/DF = 2.021, RMSEA = 0.068, IFI = 0.886, CFI = 0.884, and TLI = 0.867 (Supplementary Figure 1 and Supplementary Tables 9, 10).

Discussion

This study highlights that WM patients and their families exhibited moderate knowledge and attitudes, and suboptimal practices towards WM. The findings shed light on a critical gap in the practical aspects of disease management among this specific patient population. The research findings reveal suboptimal practices within the study population. Patients exhibited better knowledge scores than family members, suggesting potential differences in information accessibility and health literacy. This aligns with existing literatures that emphasizes the importance of tailoring educational interventions.[14,15] The observed association between education levels and knowledge scores further supports that educational background significantly influences health-related knowledge.[16] Furthermore, work status impacts knowledge, attitudes, and practices, indicating that occupational factors may play a role in shaping health-related behaviors.[17] In addition, differences in current treatments and initial reasons for seeking healthcare highlight the complexity of healthcare-seeking behavior, stressing the need for tailored interventions that account for individual circumstances. In addition, subgroup analysis based on employment status revealed that employed participants showed significantly different responses in several items, such as K5 (plasmapheresis before systemic treatment), A2 (adverse reactions and treatment adherence), P3 (avoiding crowded places), and P6 (healthy lifestyle). These findings suggest that occupational status may influence disease-related perceptions and behaviors, potentially reflecting differences in access to information, health literacy, or physical capacity for disease management. This underscores the need for socioeconomic-sensitive intervention strategies.

The correlation analysis and SEM results provided insights into the knowledge-attitudes-practices framework. Surprisingly, there was no direct effect between knowledge and attitudes, nor between knowledge and practices. This challenges the conventional belief that increased knowledge leads to more positive health behaviors. However, the practice data in our study were derived from both patient self-reports and caregiver proxy assessments, which may have introduced inconsistencies and affected the robustness of the observed relationships. Prior research has shown that proxy-reported behaviors can differ substantially from actual patient behaviors. Therefore, the lack of a direct association between knowledge and practice may partially reflect measurement bias rather than a true absence of effect.[18] The negative direct effect of attitudes on practices suggests that certain negative or fearful attitudes may discourage patients from engaging in proactive health behaviors, such as regular follow-ups or vaccination.[19]

The response for specific items provide valuable insights into the knowledge, attitudes, and practices of WM patients and their families. Patients were generally well-informed about WM, there were notable gaps in understanding regarding the incurable nature of the disease. These results align with previous research highlighting the challenges in disseminating comprehensive information about rare diseases.[20,21] Knowledge gaps were also observed in treatment decisions based on genetic mutation status, reflecting broader trends in personalized medicine.[22,23]

The desire to join patient groups for emotional support reflects the importance of peer networks. A strong inclination toward wanting to be more involved in treatment decision-making aligns with the broader trend of patient-centered care.[24] Participants' reliance on their children or personal research for information underscores the importance of healthcare providers guiding patients toward reliable sources of information.[25]

In the practice section, adherence to medical recommendations, regular follow-up appointments, and vaccination practices were encouraging. However, he low rates of influenza and pneumonia vaccination highlight the need for improvement. Targeted educational programs should be developed, focusing on specific knowledge gaps. Patient groups could be leveraged to disseminate accurate information, helping to reduce misconceptions.[26] Interventions promoting a healthy lifestyle, including regular vaccinations, should be prioritized to enhance overall disease management and quality of life.[27]

The comparison between patients and family members shows that patients generally have a slightly better understanding of WM. Family members demonstrated lower knowledge in some key aspects. While attitudes towards the disease and treatment were mostly aligned, patients were more likely to express concerns about specific aspects, such as the hereditary nature of WM. This indicates patients may have a more nuanced understanding of the implications of the disease. Patients were more consistent in attending follow-up appointments, complying with medication regimens, and maintaining preventive health practices like hand hygiene. These differences suggest that patients are more proactive in managing their health, which may be crucial for effective disease management. Discrepancies between patient self-reports and family member reports may indicate gaps in communication. Moreover, the assessment of practices based on mixed sources-self-reports from patients and proxy reports from caregivers-represents a methodological limitation. Previous studies have shown that proxy reports may overestimate or underestimate actual patient behavior. This issue may have influenced the accuracy and comparability of the practice scores across the two groups. This highlights the need for better communication and shared decision-making between patients and their families. To address these gaps, particularly in family members' knowledge and practices, targeted educational interventions could be beneficial. These may include informational workshops on WM and its management, as well as clear guidance on preventive health behaviors. Furthermore, patients and caregivers exhibit distinct informational needs, emotional burdens, and levels of engagement in disease management. Interventions aimed at patients may prioritize empowerment, self-management strategies, and reinforcement of practical health behaviors. In contrast, interventions for caregivers should address emotional support, clarification of their supportive role, and accurate understanding of treatment regimens. Tailoring interventions to the unique perspectives of each group may improve their effectiveness and ultimately enhance the patient-caregiver partnership in managing WM. Research highlights the value of involving family members in care.[28,29]

Conclusions

This study has several limitations. First, the cross-sectional design limits the ability to infer causal relationships. Second, the practice data were collected using a mix of patient self-reports and caregiver proxy assessments, which may introduce measurement bias due to well-documented differences between actual and perceived patient behaviors. Third, all responses were self- or proxy-reported, which may be subject to recall bias and social desirability effects. Additionally, participants were recruited through the Chinese WM/LPL Patient Association, which may have led to a selection bias. These individuals are likely to be more motivated, better informed, or more proactive in disease management compared to the broader WM population. Therefore, the generalizability of the findings may be somewhat limited. Additionally, although subgroup analysis by employment status was conducted, other potentially influential factors-such as gender, age, or education level-were not separately analyzed due to sample size limitations. Future studies should include more comprehensive subgroup analyses to better understand how these variables shape KAP profiles and inform targeted interventions. Moreover, longitudinal designs and objective measures are also needed to capture temporal changes and enhance the robustness of conclusions.

In conclusion, WM patients and their family members had moderate levels of knowledge, attitudes, and practices toward WM, based on the scoring classification used in this study. By addressing patients' attitudes and offering tailored support, healthcare professionals can significantly enhance the overall well-being and treatment outcomes of individuals affected by WM.

Data Sharing Statement

All data generated or analysed during this study are included in this published article and its supplementary information files.

Ethics Approval and Consent to Participate

This work has been carried out in accordance with the Declaration of Helsinki (2000) of the World Medical Association. The study was approved by the Clinical Research Ethics Committee of the First Affiliated Hospital of Zhejiang University (The first college of Zhejiang University, 2023 No. 0841) and written informed consent was obtained from all participants.

Author Contributions

All authors made a significant contribution to the work reported, whether that is in the conception, study design, execution, acquisition of data, analysis and interpretation, or in all these areas; took part in drafting, revising or critically reviewing the article; gave final approval of the version to be published; have agreed on the journal to which the article has been submitted; and agree to be accountable for all aspects of the work.

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Disclosure

The authors declare that they have no competing interests.

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