

Validation and psychometric properties of the Consumer Financial Protection Bureau Financial Well-Being Scale (CFPB-FWBS) for Polish family caregivers of individuals with rare diseases

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ABSTRACT

Introduction. Caregivers of individuals with rare diseases (RDs) face numerous challenges related to health-care access, physical and emotional strain, social isolation, and psychological distress; however, financial burden often has the most significant impact on family well-being and the ability to provide adequate care. This study aimed to validate the Consumer Financial Protection Bureau Financial Well-Being Scale (CFPB-FWBS) among caregivers of individuals with RD in Poland.

Material and methods. Based on a sample of 942 family caregivers of individuals diagnosed with one of 159 RDs, the validation procedure involved exploratory and confirmatory factor analyses, along with evaluation of internal consistency and interpretability.

Results. Analyses supported the unidimensional structure of the Polish CFPB-FWBS. Inter-item correlations were moderate to strong ($r = .48-.68$), except for Q9, which showed a weaker correlation. PCA confirmed a dominant first component (eigenvalue ≈ 5.7 , explaining $\sim 57\%$ of variance), with all items loading adequately. Cronbach's alpha was high ($\alpha = 0.92$), and no item removal improved reliability. CFA indicated good model fit ($\chi^2/df = 5.67$, CFI = 0.968, TLI = 0.959, SRMR = 0.03, RMSEA = 0.07). Latent scores (0–100 scale) approximated a normal distribution ($M = 50.5$, $SD = 12.1$, range = 14–86).

Conclusions. The Polish version of the CFPB-FWBS demonstrates strong reliability, structural validity, and meaningful score distributions among caregivers of individuals with rare diseases. These findings support its use as a standardised measure of financial well-being in Poland, enabling research, policy development, and international comparisons.

Introduction

Although no universal definition of a rare disease (RD) exists, the European Union (EU) defines RDs as conditions affecting fewer than 1 in 2,000 individuals [1,2]. However, some diseases occur even less frequently: ultra-rare diseases are those found in fewer than 1 in 100,000 people, while hyper-rare diseases affect fewer than 1 in 1,000,000 [3,4]. Current estimates indicate that more than 10,000 distinct RDs have been identified [5], impacting up to 35 million people in the EU, over 350 million worldwide, and approximately 2.5–3 million individuals in Poland [6].

Despite wide variation in aetiology, clinical manifestations, course, and prognosis, RDs share several characteristics. Approximately 80% of these conditions are of genetic origin, with about 65% resulting in severe clinical symptoms. Children account for half of all cases, and nearly one-third die before reaching the age of five [7]. Furthermore, 95% of RDs still lack approved therapy [8–10].

Challenges related to RDs extend beyond patients, placing substantial emotional, physical, financial, and organisational demands on families and caregivers, who often require continuous support and guidance in navigating fragmented healthcare and social systems [11–14]. Families frequently face prolonged diagnostic delays, limited referral pathways, and a lack of coordinated care, often having to manage services independently [14–16]. Access to genetic testing, counselling, and innovative therapies is commonly restricted, while institutional and psychological support remains insufficient, forcing reliance on out-of-pocket resources [11,17]. A common barrier is low RD awareness among the public, policymakers, and healthcare professionals, resulting in most primary care physicians reporting a lack of expertise and feeling unprepared to care for patients with RD. This is unsurprising, as such cases represent only about 1.6% of visits [22,23].

These systemic barriers translate into significant burdens for caregivers, encompassing physical strain (e.g., fatigue, injury), emotional distress, social isolation, and psychological exhaustion, which reduce quality of life and increase the risk of depression, anxiety, and caregiver burden. Consequently, many caregiv-

ers require psychiatric support. Financial strain is also considerable, involving frequent medical visits, high out-of-pocket costs, and disparities in insurance coverage, which force many parents to reduce their working hours or leave employment entirely [24–26]. Research consistently shows that RDs generate both direct (e.g., therapies, equipment, home modifications) and indirect (notably, caregiver productivity loss) costs, further compounded by the adverse effects of caregiving on physical and mental health, which undermines both family well-being and economic stability [27,28].

Although earlier research has shown that financial well-being is an essential predictor of caregivers' quality of life and perceived burden, no dedicated instrument exists to evaluate their economic strain. This study addresses this gap by validating the Consumer Financial Protection Bureau Financial Well-Being Scale (CFPB-FWBS) [29] among Polish caregivers of individuals with RDs and by examining its psychometric properties, including reliability, validity, and factor structure in this specific population.

Methods

Study Design

A cross-sectional study was conducted in 2024, in accordance with the Strengthening the Reporting of Observational Studies in Epidemiology (STROBE) guidelines [30]. Data were collected through a self-administered, anonymous, computer-assisted web-based survey assessing the association between caregiving for a person with an RD and caregivers' financial well-being.

Participants and Setting

Participants were Polish-speaking adults (≥ 18 years) who were parents or family caregivers of individuals with a confirmed RD diagnosis, had internet access, and provided informed consent. Due to the absence of a national RD registry, caregivers were recruited via convenience sampling, with patient associations, foundations, and organisations distributing the survey link through their websites and social media.

Table 1 shows the composition of the caregiver sample according to gender (male/female) and age group (16–29, 30–39, 40–49, 50+), along

Table 1. Sample description by gender and age of caregivers.

Age (years)	Male	Female	Total
16-29	2 (1.5%)	32 (3.9%)	34 (3.6%)
30-39	44 (33.8%)	337 (41.5%)	381 (40.4%)
40-49	64 (49.2%)	350 (43.1%)	414 (43.9%)
50 and more	20 (15.4%)	93 (11.5%)	113 (12.0%)
	130 (13.8%)	812 (86.2%)	942 (100%)

with totals for the entire sample. The table provides counts and percentages, directly comparing the age structure within each gender group and against the overall distribution.

The analytical sample comprised 942 caregivers, of whom 812 were women (86.2%), and 130 were men (13.8%). Age distribution was: 16–29, 34 (3.6%; men 2 [1.5%], women 32 [3.9%]); 30–39, 381 (40.4%; men 44 [33.8%], women 337 [41.5%]); 40–49, 414 (43.9%; men 64 [49.2%], women 350 [43.1%]); 50+, 113 (12.0%; men 20 [15.4%], women 93 [11.5%]). Thus, participation was concentrated among those aged 30–49 (795/942; 84.3%), with relatively few in the 16–29 age group (3.6%) and among those aged 50 and over (12.0%). Men were more likely to be in the 40–49 age group (49.2%) than women (43.1%), whereas women were over-represented in the 30–39 age group (41.5% vs. 33.8% for men). At the same time, although the relatively low number of male participants may suggest a potential gender bias, it should be noted that convenience sampling typically reflects the broader pattern of a marked under-representation of men among family caregivers [14,31,32].

Ethical Issues

The study was conducted in accordance with the principles outlined in the Declaration of Helsinki. It was approved by the Bioethics Committee of the Poznan University of Medical Sciences (KB–228/24, March 13, 2024). Informed written consent was obtained electronically via the online survey ("I agree" option).

Participation was voluntary, anonymous, and confidential, with the right to withdraw at any time. No personal identifiers were collected, and although some questions could be emotionally sensitive, respondents could skip items or discontinue participation. No financial compensation was provided.

Research Questionnaire

The survey questionnaire used in this study consisted of two sections. The first included closed-ended, single-choice questions concerning caregivers' sociodemographic characteristics. The second incorporated the CFPB-FWBS [29], a freely available, standardised instrument developed in the United States to measure financial well-being, understood as both economic security and the freedom to manage short- and long-term financial needs. The scale comprises ten Likert-type items, producing raw and standardised scores that enable comparisons across populations and allow for examining associations with other variables:

How well does this statement describe you or your situation?

- Q1. I could handle a major unexpected expense
- Q2. I am securing my financial future
- Q3. Because of my financial situation, I feel like I will never have the things I want in life
- Q4. I can enjoy life because of the way I'm managing my money
- Q5. I am just getting by financially
- Q6. I am concerned that the money I have or will save won't last

How often does this statement apply to you?

- Q7. Giving a gift for a wedding, birthday, or other occasion would put a strain on my finances for the month
- Q8. I have money left over at the end of the month
- Q9. I am behind with my finances
- Q10. My finances control my life

Since no Polish version of the CFPB-FWBS was available, the tool was back-translated by two independent bilingual translators and adapted to the Polish context. It was then pilot-tested in two small groups (caregivers of children with

chronic illnesses and healthy adults), confirming its clarity, cultural relevance, and internal consistency, which supported its suitability for use in the present study.

Data Collection

The data were collected between March and August 2024 among family caregivers of individuals with RDs, with the assistance of several patient organisations, foundations, and associations (see Acknowledgements). After obtaining their permission, the research coordinator distributed an invitation letter with a link to the online questionnaire via their websites and social media. In total, 73 patient groups were contacted, many of which represented multiple rare conditions or the broader RD community. Participants provided informed consent electronically before completing the survey, which took approximately 20–25 minutes. To increase response rates, three reminders were sent during the study period.

Statistical Analysis

Descriptive statistics were first computed for all items. Inter-item correlations were examined to assess initial patterns of association. Principal Component Analysis (PCA) was conducted

to evaluate unidimensionality, with eigenvalues, scree plot, and component loadings used to guide interpretation. Reliability was assessed using Cronbach's alpha with 95% confidence intervals (CI) and item-deletion diagnostics. Confirmatory Factor Analysis (CFA) was then performed using polychoric correlations and a robust weighted least squares estimator, with factor variance fixed to 1 for identification. Model fit was evaluated with multiple indices, including the chi-square test, the Comparative Fit Index (CFI), the Tucker–Lewis Index (TLI), the Root Mean Square Error of Approximation (RMSEA) with 90% CI, and the Standardised Root Mean Square Residual (SRMR). Standard thresholds for acceptable fit (CFI/TLI ≥ .95, RMSEA ≤ .06–.08, SRMR ≤ .08) were applied. Normative data were generated for the total scale scores, stratified by gender. All statistical analyses were conducted using R Statistical Software (version 4.3.1; R Foundation for Statistical Computing) [34].

Results

Figure 1 shows the matrix of correlations between the ten CFPB-FWBS items. After aligning the item

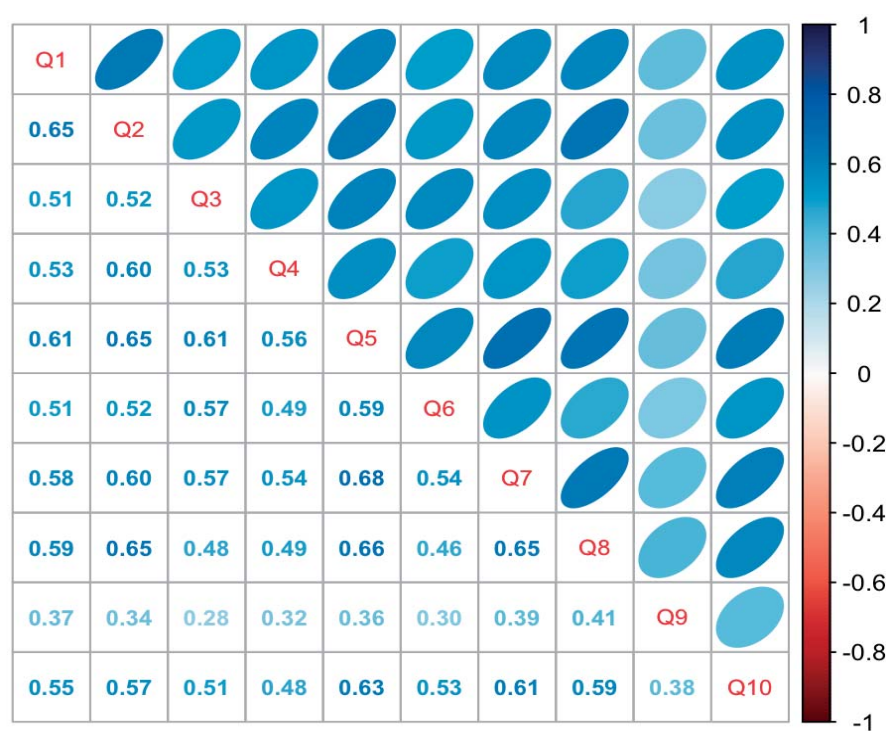


Figure 1. Correlation plot for 10 items of the CFPB-FWBS.

directions, all correlations are positive. Most of the associations between pairs of items fall within the moderate to strong range (approximately $r = .48-.68$), indicating that the items share a substantial amount of common variance. The strongest associations are observed among items measuring perceived security and financial management (Q1–Q8 and Q10), consistent with a largely unidimensional structure.

A notable exception is Item Q9 ('I am behind with my finances', reverse-coded), which shows markedly weaker correlations with the rest of the scale (approximately $r = .28-.41$). This attenuation is evident, suggesting that Q9 may capture a more specific aspect of financial strain relating to arrears rather than the broader sense of economic security and control targeted by the remaining items. Consequently, we anticipate that Q9 will contribute less to internal consistency and exhibit a lower factor loading in subsequent analyses, a point we examine formally below.

Principal Component Analysis

Next, we implemented principal component analysis (PCA) to examine the scale's unidimensionality before confirmatory modelling. PCA provides a model-free summary of how the ten items

covary by reducing them to components extracted from the inter-item correlation matrix. This step addresses two central questions regarding score validity: (a) whether a single dominant component accounts for a substantial proportion of the variance, which would support a unidimensional total score, and (b) whether any items contribute weakly or inconsistently to the aggregated score.

The scree plot in **Figure 2** shows a dominant first component, followed by a sharp drop and a long, shallow tail. The first eigenvalue is approximately 5.7–5.8, accounting for around 57–58% of the total variance. The second eigenvalue is approximately 0.8, and all subsequent eigenvalues are less than or equal to 0.6. According to the Kaiser criterion (retaining eigenvalues > 1) and the apparent elbow after the first point, there is strong evidence in favour of a unidimensional structure. However, given that the second eigenvalue is < 1 and the curve flattens immediately, any additional component would capture only minor, item-specific variance rather than a coherent secondary dimension.

Table 2 reports the PCA loadings and the item complexity. A clear pattern emerges: Items Q1–Q8 and Q10 load moderately to firmly on Compo-

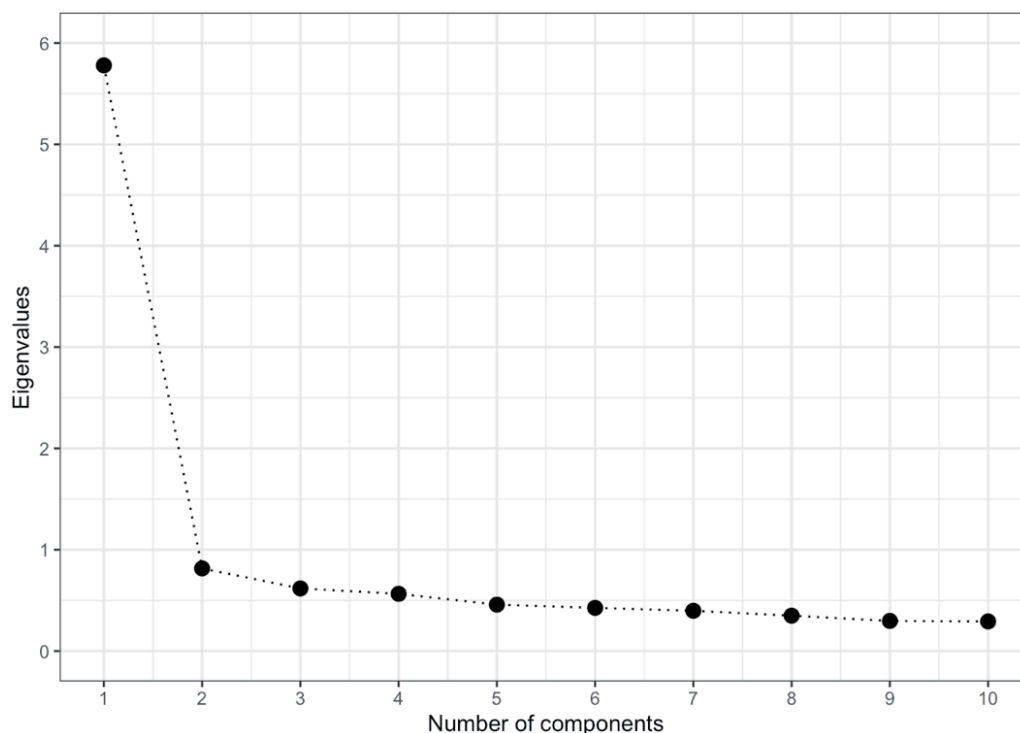


Figure 2. Scree Plot.

Table 2. PCA results for two components: number of items reduced based on factor loadings values, and complexity measure.

Item	Component 1
Q1	0.784
Q2	0.813
Q3	0.739
Q4	0.732
Q5	0.848
Q6	0.728
Q7	0.819
Q8	0.795
Q9	0.520
Q10	0.775

Table 3. Fit indices for the unidimensional solution of the CFPB-FWBS.

Chisq	df	Chisq/df	p-value	CFI	TLI	SRMR	RMSEA	RMSEA – 90%CI	RMSEA + 90%CI
198.441	35	5.67	<0.001	0.968	0.959	0.03	0.07	0.061	0.08

nent 1 (approximately 0.65–0.80; maximum Q5 loading of 0.804). Q9 shows the lowest loading on Component 1 (0.520); however, its primary loading remains adequate.

According to typical item-reduction rules (items with salient loading on the dominant component are retained, and items with high complexity are avoided), only Q9 could be recognised as flagged for exclusion from a unidimensional scale. No other item meets the removal criteria. However, in practice, retaining Q9 is helpful for comparability or for capturing strain specific to arrears; hence, we proceed further with all ten items.

Reliability analysis

The Cronbach's alpha for all ten items was 0.92 (standardised $\alpha = 0.92$), with a 95% confidence interval (CI) of 0.91–0.93 and an average inter-item correlation of 0.57. This indicates high internal consistency for the retained items. Item-deletion diagnostics revealed that removing no item would meaningfully improve reliability: alphas if dropped ranged from 0.90 to 0.92 (the lowest being when Q5 was dropped, with an alpha of approximately 0.90). The reliability evidence supports the creation of a unidimensional scale based on questions 1-10; removing any single item would not yield a higher reliability score, and all retained items demonstrate adequate discrimination.

Confirmatory factor analysis

Guided by the PCA and reliability results, we tested a single-factor CFA model for the CFPB scale using all items (see Table 3). As the items are ordinal, we estimated the model using polychoric correlations with a robust estimator (factor variance fixed to 1 for identification). We evaluated the model's fit using the following criteria: χ^2/df , CFI, TLI, RMSEA (90% CI), and SRMR, and the standard thresholds: CFI/TLI $\geq .95$, RMSEA $\leq .06$ –.08, and SRMR $\leq .08$.

The unidimensional model demonstrated satisfactory overall fit. Although the chi-squared was significant (i.e., $\chi^2 = 198.44$, $df = 35$, $p < .001$; chi-squared to degrees of freedom ratio = 5.67), this is to be expected with $N = 942$. Practical indices were strong: the CFI and TLI exceeded conventional thresholds at 0.968 and 0.959, respectively; the SRMR indicated perfect residual fit at 0.03; and the RMSEA fell within the acceptable range at 0.07, with 90% CI [0.061, 0.08]. Together, these results support a single-factor representation of the ten items.

Latent scores of the CFPB-FWBS for the Polish population of caregivers of persons with RDs

A descriptive analysis of the normalised CFPB-FWBS scores was conducted. Responses to each item were coded on a 0–4 scale, and the total score was derived in accordance with the scoring

instructions provided by the scale's authors (30). The recommended interpretive bands are as follows: Very low (0–29), Low (30–37), Medium low (38–49), Medium high (50–57), High (58–67), and Very high (68–100). **Figure 3** displays the distribution of CFPB-FWBS latent scores, ranging from 0 to 100, calculated as a CFA-weighted sum of all ten items.

Figure 3 shows a roughly symmetric, uni-modal distribution centred near 50 using the CFPB's scoring algorithm (0–100). **Table 4** indicates a mean of 50.54 (SD 12.08) and a median of 50.00, with a skewness of –0.001 and a kurtosis of 2.892. These values are consistent with a normal distribution. The Shapiro-Wilk test ($W = 0.996$, $p = 0.010$) rejects the assumption of normality, likely due to its sensitivity to large samples. Yet, the deviation is slight, and the histogram remains close to bell-shaped.

Empirical scores in a sample range from 14 to 86, with quartiles at $Q1 = 42.0$ and $Q3 = 59.0$ (IQR

= 17). Thus, the central 50% of caregivers fall within the Medium Low (38–49), Medium High (50–57), and High (58–67) bands. The mode around 50–55 suggests that many respondents are in the Medium High category. Visual inspection

Table 4. Descriptive characteristics of latent scores for the CFPB-FWBS for the Polish population of caregivers of persons with RDs

Statistic	CFPB-FWBS
Mean	50.54
Standard deviation	12.08
Skewness	-0.001
Kurtosis	2.892
Shapiro-Wilk statistic	0.996
Shapiro-Wilk p-value	0.010
Minimum	14.0
Q1	42.0
Median	50.0
Q3	59.0
Maximum	86.0

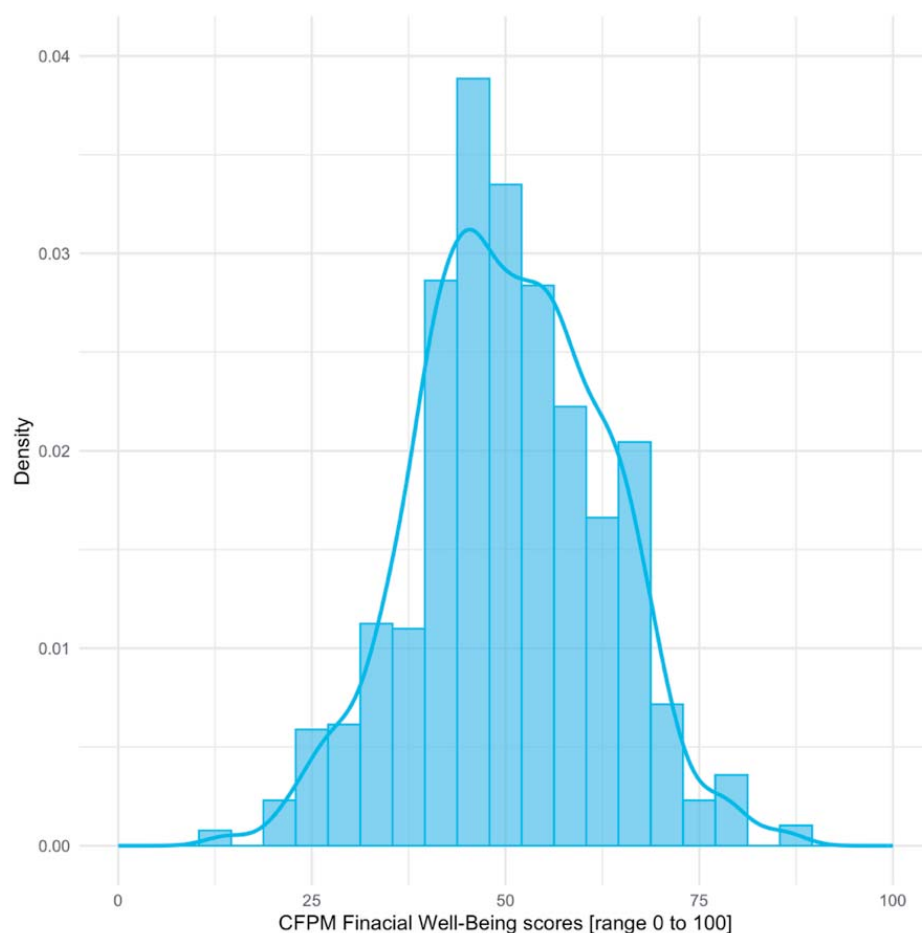


Figure 3. Histogram and density plot for the CFPB-FWBS for the Polish population of caregivers of persons with RDs

reveals thin tails, indicating relatively few cases in the Very Low (0–29) or Very High (68–100) ranges, with no evidence of floor or ceiling compression.

Overall, the score distribution is evenly spread across the interpretive bands, with most caregivers clustering in the medium to high financial well-being range—an empirical profile that supports subsequent subgroup comparisons and norm-referenced interpretation.

Normative data for the CFPB-FWBS

Normative data for the CFPB-FWBS were established using a large sample of Polish caregivers of individuals with rare diseases. The norms are stratified by gender, enabling researchers to interpret an individual's score in relation to population-specific reference values (see **Table 5**). We provide the following information to gauge each subgroup's distribution and potential score compression: means, standard errors, percentile-based summaries (Q1, median, Q3), minima, and maxima. These norms can be used for several purposes, such as benchmarking individuals or cohorts, identifying demographic segments with relatively lower financial well-being, and informing eligibility thresholds in screening or programme evaluation. As subgroup sizes vary, interpretation should consider standard errors and the width of interquartile ranges. Taken together, the norms enhance the practical utility of the scale by providing a clear demographic-specific context for CFPB-FWBS scores in this population.

Table 5 provides gender-stratified reference values. On average, men have a higher central tendency than women (mean = 53.8, standard error (SE) = 1.10 vs. mean = 50.0, SE = 0.42), which equates to a difference of ~3.8 points on the 0–100 scale (a small effect given the overall standard deviation (SD) of approximately 12). The medians mirror this pattern (55 vs. 50). However, quartiles indicate substantial overlap: men Q1–Q3 = 46–63 (IQR = 17) and women Q1–Q3 = 42–58 (IQR = 16). Thus, while men score higher on average, the distributions are similar.

Relative to the CFPB interpretive bands, both medians fall within the 'Medium High' category (50–57). For men, Q3 = 63 falls into the High category (58–67), whereas for women, Q3 = 58 sits at the High threshold. Q1 places more women in the Medium Low category (38–49) than

Table 5. CFPB-FWBS scale norms by gender for the Polish population of caregivers of persons with RDs

Statistic	Male	Female
Mean	53.8	50.0
Standard error of the mean	1.10	0.42
Minimum	14.0	14.0
Q1	46.0	42.0
Median	55.0	50.0
Q3	63.0	58.0
Maximum	86.0	86.0

men (42 vs. 46). The observed ranges (14–86 in both groups) suggest there is no compression of the floor or ceiling. Standard errors are smaller among women, reflecting the larger subgroup. Overall, these norms indicate that men have modestly higher financial well-being, but substantial overlap between the genders supports the use of a standard cut-point system for practical interpretation.

Discussion

Caring for a person with RD results in a significant economic burden, encompassing both direct medical costs and indirect productivity losses [24–28]. In the United States, 379 RDs generated an annual cost of \$997 billion, of which \$449 billion (45%) were direct medical costs, primarily hospitalisations (32%). Prescription drugs (18%). In comparison, \$437 billion (44%) stemmed from productivity losses such as absenteeism, presenteeism, and early retirement [34]. Another U.S. study of 24 RDs reported average per-patient costs of \$266,000, ten times higher than for common conditions, with indirect costs making up to 45% of the total [26]. Similar findings were reported in China, where annual direct medical costs exceeded household income, with an additional 40–45% of income devoted to non-medical and indirect expenses, posing a high or extremely high burden on over half of families [35].

In Poland, studies on tuberous sclerosis complex showed that indirect costs account for 17–39% of the total burden [36]. Similarly, for adult patients with cystic fibrosis, the average annual treatment cost was €19,581, with 70% related to direct costs, mainly pharmacotherapy (€10,171) and hospitalisations (€2,878), and 30% to indire-

ct expenses, primarily lost productivity (€5,706) [37]. A recent study on parents of individuals with Angelman syndrome reported that while one-third of caregivers utilised psychological or psychiatric services, 96.2% of their costs (€31,356.79 in 2024) were privately funded [27].

European studies further confirm the high costs of RDs. Direct medical expenses for Dravet syndrome average €16,000 annually, with hospitalisations and related care accounting for the majority of expenditures [38]. In Germany, annual costs of Duchenne muscular dystrophy were €78,913 and of Becker muscular dystrophy €39,060, with informal care, productivity losses, and rehabilitation as main expenses, all rising with disease progression [39]. Numerous other studies indicate that indirect costs, lost income, reduced working hours, and job resignations remain the most significant burden [40–42]. All these findings demonstrate that the economic consequences of RDs extend far beyond healthcare expenditures, placing a profound strain on families.

This study presents the first psychometric evaluation of the Polish adaptation of the CFPB-FWBS among family caregivers of people with RDs [29]. The results indicate that the instrument functions reliably and demonstrates solid structural validity in this distinct cultural and caregiving setting.

The CFPB-FWBS was initially designed in the United States as a standardised, publicly accessible measure of financial well-being. It captures not only objective aspects of household finances but also subjective perceptions of stability and security. The Consumer Financial Protection Bureau conceptualises financial well-being as a state in which individuals can meet their present and ongoing financial commitments, feel confident about their future, and maintain the freedom to make choices that bring satisfaction in daily life. This definition was developed through extensive empirical research and qualitative input from U.S. consumers and financial experts. The instrument operationalises four interconnected domains: management of everyday financial demands, resilience to unexpected shocks, progress toward longer-term financial goals, and the freedom to make discretionary choices that improve quality of life [29].

Our analyses were consistent with the original CFPB report (CFPB, 2017), which documen-

ted a unidimensional factor structure. Principal component analysis revealed a dominant underlying factor, while confirmatory factor analysis provided strong support for a single-factor solution. Fit indices were uniformly favourable (CFI = 0.968, TLI = 0.959, SRMR = 0.03, RMSEA = 0.07), indicating that the scale performs well in this population. Although the chi-square statistic reached significance, this is expected given the large sample size and does not compromise the interpretation of the other fit indices.

Reliability was also satisfactory. Cronbach's alpha exceeded standard benchmarks, and all items loaded meaningfully onto the latent construct. These findings parallel results from other adaptations. For instance, the Brazilian Portuguese version reported by Howat-Rodrigues et al. also confirmed a unidimensional structure [43]. The consistency of results across cultural contexts underscores the instrument's robustness.

At the respondent level, scores rescaled to a 0–100 metric displayed a meaningful distribution, reflecting variation in caregivers' financial circumstances. This heterogeneity likely reflects diverse caregiving demands, household resources, and differential access to social and health system support. Caregivers of individuals with RDs often face particularly acute challenges, including high direct medical costs, uncovered out-of-pocket expenses, and lost income due to reduced labour market participation. The CFPB-FWBS's ability to capture such gradations of perceived financial well-being underscores its value for both policy and research applications.

Although initially designed for consumer-focused use in the United States, the CFPB-FWBS has since been applied across a wide array of settings, both domestically and internationally, further supporting its versatility. Research with individuals living with diabetes has shown consistently lower financial well-being compared with those without the condition, with marked disparities across racial and ethnic groups [44]. Among health professionals and trainees, the scale has been sensitive to external crises, such as Lebanon's financial collapse, during which scores declined sharply, and to structural factors, such as socioeconomic background, income, and student debt [45]. In U.S. family medicine residents, scores have typically fallen in the mid-range, with progression in training and financial education

linked to improvements [46]. Beyond these contexts, studies among trauma survivors in China revealed widespread economic insecurity, while research with older cancer patients in India found that most participants experienced poor financial well-being [47]. During the COVID-19 pandemic, the instrument was also used to assess otorhinolaryngologists in India, detecting sharp income-related declines, with higher scores observed in older and more experienced physicians [48].

Importantly, the CFPB-FWBS not only measures financial standing but also helps illuminate the broader impact of financial strain. Lower scores have been tied to psychological distress, depressive symptoms, and post-traumatic stress among trauma survivors [49]. Among patients with cancer, poorer financial well-being correlated with higher distress, greater caregiver burden, and worse mental health outcomes. More broadly, evidence shows that over-indebtedness is associated with higher rates of depression and anxiety, echoing social causation theories that link economic hardship with mental health difficulties. Lower financial well-being has also been consistently associated with reduced quality of life across multiple domains, as well as with socioeconomic vulnerabilities such as low income, debt, lack of insurance, illiteracy, and cognitive impairment.

The validation of the CFPB-FWBS in a Polish caregiving population, therefore, contributes to the international literature on financial well-being. In addition to its methodological value, the instrument provides a practical means for assessing both financial strain and resilience in health economics, social policy, and psychosocial research. Conceptually, the findings resonate with frameworks that integrate subjective perceptions and objective resources in defining financial well-being [50]. Future research should extend this work by assessing stability over time, evaluating predictive validity with health or quality-of-life outcomes, and examining measurement invariance across subgroups such as gender, employment status, and rural versus urban residence.

Several limitations should be acknowledged. The study drew on a large but non-random sample, which restricts generalizability. Its cross-sectional design prevents conclusions about sensitivity to change or causal relationships. Finally, although a unidimensional structure was

supported, multidimensional aspects of financial well-being, such as short-term versus long-term security, could be relevant in specific subgroups and warrant further exploration. As only 130 fathers completed the survey, the study is constrained by an implicit gender bias. Furthermore, reliance on online recruitment may have introduced selection bias.

Despite these caveats, the present validation strengthens confidence in the CFPB-FWBS as a reliable and valid instrument for assessing financial well-being in Poland. Its application among caregivers of individuals with RDs addresses a crucial methodological gap while also shedding light on the economic challenges faced by this vulnerable group. By enabling standardised assessment, the CFPB-FWBS provides a foundation for targeted interventions, policy initiatives, and international comparisons to alleviate financial vulnerability among caregiving families.

Abbreviations

CFPB-FWBS: the Consumer Financial Protection Bureau Financial Well-Being Scale; EU: the European Union; RDs: rare diseases.

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Ethics Approval and Consent to Participate

This study was performed in line with the principles of the Declaration of Helsinki. Ethics and research governance approval were obtained from the PUMS Bioethics Committee (KB-228/24). Informed written consent was obtained from all individual participants in the study.

Consent for publication

Not applicable

Clinical trial number

Not applicable

Availability of data and materials

The data supporting this study's findings are not openly available due to reasons of sensitivity and are available from the corresponding author upon reasonable request.

Conflict of interest statement

The authors declare that they have no conflict of interest.

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Authors' contributions

Dariusz Walkowiak and Jan Domaradzki contributed to the conception and design of the study. Jan Domaradzki collected the data and coordinated the study. Dariusz Walkowiak and Piotr Jabkowski performed material preparation and analysis. Piotr Jabkowski prepared tables and Figures. All authors contributed to the preparation of the first draft of the manuscript and read and approved the final manuscript. All authors contributed equally to this paper.

References

1. The Lancet Global Health null. The landscape for rare diseases in 2024. *Lancet Glob Health*. 2024 Mar;12(3):e341. [https://doi.org/10.1016/S2214-109X\(24\)00056-1](https://doi.org/10.1016/S2214-109X(24)00056-1)
2. Ministerstwo Zdrowia [Internet]. [cited August 14 2025]. Rada Ministrów przyjęła Plan dla Chorób Rzadkich na lata 2024-2025 - Ministerstwo Zdrowia - Portal Gov.pl. <https://www.gov.pl/web/zdrowie/rada-ministrow-przyjela-plan-dla-chorob-rzadkich-na-lata-2024-2025>
3. Nguengang Wakap S, Lambert DM, Olry A, Rodwell C, Gueydan C, Lanneau V, et al. Estimating cumulative point prevalence of rare diseases: analysis of the Orphanet database. *Eur J Hum Genet*. 2020 Feb;28(2):165–73. <https://doi.org/10.1038/s41431-019-0508-0>
4. Smith CIE, Bergman P, Hagey DW. Estimating the number of diseases – the concept of rare, ultra-rare, and hyper-rare. *iScience* [Internet]. 19 August 2022 [cited 28 July 2025];25(8). [https://www.cell.com/iscience/abstract/S2589-0042\(22\)00970-1](https://www.cell.com/iscience/abstract/S2589-0042(22)00970-1)
5. Haendel M, Vasilevsky N, Unni D, Bologna C, Harris N, Rehm H, et al. How many rare diseases are there? *Nat Rev Drug Discov*. 2020 Feb;19(2):77–8. <https://doi.org/10.1038/d41573-019-00180-y>

6. Kancelaria Prezesa Rady Ministrów [Internet]. [cited 14 September 2025]. Projekt uchwały Rady Ministrów w sprawie przyjęcia dokumentu Plan dla Chorób Rzadkich na lata 2024-2025 - Kancelaria Prezesa Rady Ministrów - Portal Gov.pl. <https://www.gov.pl/web/premier/projekt-uchwaly-rady-ministrow-w-sprawie-przyjecia-dokumentu-plan-dla-chorob-rzadkich-na-lata-2024-2025>
7. What is a rare disease? [Internet]. EURORDIS-Rare Diseases Europe. [cited 28 August 2025]. <https://www.eurordis.org/information-support/what-is-a-rare-disease>
8. RARE Disease Facts [Internet]. Global Genes. [cited 28 August 2025]. <https://globalgenes.org/rare-disease-facts>
9. Domike R, Raju GK, Sullivan J, Kennedy A. Expediting treatments in the 21st century: orphan drugs and accelerated approvals. *Orphanet Journal of Rare Diseases*. 2024 Nov;19(1):418. <https://doi.org/10.1186/s13023-024-03398-1>
10. Fermaglich LJ, Miller KL. A comprehensive study of the rare diseases and conditions targeted by orphan drug designations and approvals over the forty years of the Orphan Drug Act. *Orphanet J Rare Dis*. 2023 Jun;18(1):163. <https://doi.org/10.1186/s13023-023-02790-7>
11. Claessens Z, Vanneste A, Van Isterdael C, Verbeke C, Wens I, Huys I. Criteria to evaluate unmet health-related needs of persons living with rare diseases and their caregivers: rapid literature review and stakeholder consultations. *Orphanet Journal of Rare Diseases*. 2025 Jul;20(1):321. <https://doi.org/10.1186/s13023-025-03838-6>
12. McMullan J, Lohfeld L, McKnight AJ. Needs of informal caregivers of people with a rare disease: a rapid review of the literature. *BMJ Open*. 2022 Dec;12(12):e063263. <https://doi.org/10.1136/bmjopen-2022-063263>
13. Rihm L, Dreier M, Rezvani F, Wiegand-Grefe S, Dirmaier J. The psychosocial situation of families caring for children with rare diseases during the COVID-19 pandemic: results of a cross-sectional online survey. *Orphanet J Rare Dis*. 2022 Dec;17:449. <https://doi.org/10.1186/s13023-022-02595-0>
14. Domaradzki J, Walkowiak D. Invisible patients in rare diseases: parental experiences with the healthcare and social services for children with rare diseases. A mixed method study. *Sci Rep*. 2024 Jun;14(1):14016. <https://doi.org/10.1038/s41598-024-63962-4>
15. Currie G, Szabo J. „It is like a jungle gym, and everything is under construction”: The parent's perspective of caring for a child with a rare disease. *Child Care Health Dev*. 2019 Jan;45(1):96–103. <https://doi.org/10.1111/cch.12628>
16. Anderson M, Elliott EJ, Zurynski YA. Australian families living with rare disease: experiences of diagnosis, health services use and needs for psychosocial support. *Orphanet J Rare Dis*. 2013 Feb;8:22. <https://doi.org/10.1186/1750-1172-8-22>
17. Al-Attar M, Butterworth S, McKay L. A quantitative and qualitative analysis of patient group narratives suggests common biopsychosocial red flags of undiagnosed rare disease. *Orphanet J Rare Dis*. 2024 Apr;19:172. <https://doi.org/10.1186/s13023-024-03143-8>
18. Ramalle-Gómara E, Domínguez-Garrido E, Gómez-Eguílaz M, Marzo-Sola ME, Ramón-Trapero JL, Gil-de-Gómez J. Education and information needs for physicians about rare diseases in Spain. *Orphanet J Rare Dis*. 2020 Jan;15(1):18. <https://doi.org/10.1186/s13023-019-1285-0>
19. Walkowiak D, Domaradzki J. Are rare diseases overlooked by medical education? Awareness of rare diseases among physicians in Poland: an explanatory study. *Orphanet J Rare Dis*. 2021 Sep;16(1):400. <https://doi.org/10.1186/s13023-021-02023-9>
20. Zhang H, Xiao Y, Zhao X, Tian Z, Zhang SY, Dong D. Physicians' knowledge on specific rare diseases and its associated factors: a national cross-sectional study from China. *Orphanet J Rare Dis*. 2022 Mar;17(1):120. <https://doi.org/10.1186/s13023-022-02243-7>
21. Walkowiak D, Bokayeva K, Miraleeva A, Domaradzki J. The Awareness of Rare Diseases Among Medical Students and Practicing Physicians in the Republic of Kazakhstan. An Exploratory Study. *Front Public Health*. 2022 Apr;10:872648. <https://doi.org/10.3389/fpubh.2022.872648>
22. Rohani-Montez SC, Bomberger J, Zhang C, Cohen J, McKay L, Evans WRH. Educational needs in diagnosing rare diseases: A multinational, multispecialty clinician survey. *Genet Med Open*. 2023 Apr;1(1):100808. <https://doi.org/10.1016/j.gimo.2023.100808>
23. Jo A, Larson S, Carek P, Peabody MR, Peterson LE, Mainous AG. Prevalence and practice for rare diseases in primary care: a national cross-sectional study in the USA. *BMJ Open*. 2019 Apr;9(4):e027248. <https://doi.org/10.1136/bmjopen-2018-027248>
24. Angelis A, Kanavos P, López-Bastida J, Linertová R, Oliva-Moreno J, Serrano-Aguilar P, et al. Social/economic costs and health-related quality of life in patients with epidermolysis bullosa in Europe. *Eur J Health Econ*. 2016 Apr;17 Suppl 1(Suppl 1):31–42. <https://doi.org/10.1007/s10198-016-0783-4>
25. Chung CCY, Ng NYT, Ng YNC, Lui ACY, Fung JLF, Chan MCY, et al. Socio-economic costs of rare diseases and the risk of financial hardship: a cross-sectional study. *Lancet Reg Health West Pac*. 2023 Feb;34:100711. <https://doi.org/10.1016/j.lanwpc.2023.100711>
26. Andreu P, Karam J, Child C, Chiesi G, Cioffi G. The Burden of Rare Diseases: An Economic Evaluation. <https://www.ultragenyx.com/wp-content/uploads/2024/05/Chiesi-EconomicBurdenofRareDiseasesFeb.-2022.pdf>
27. Domaradzki J, Pospieszńska-Martysiuk K, Dianow H, Węgrzyn J, Walkowiak D. Psychological and psychiatric service use among family caregivers of individuals with Angelman Syndrome: A cross-sectional study. *Psychiatr Pol*. 2025;1–16. <https://doi.org/10.12740/PP/OnlineFirst/206031>
28. Strzelczyk A, Schubert-Bast S, Bast T, Bettendorf U, Fiedler B, Hamer HM, et al. A multicenter, matched case-control analysis comparing burden-of-illness in Dravet syndrome to refractory epilepsy and seizure remission in patients and caregivers in Germa-

- ny. *Epilepsia*. 2019 Aug;60(8):1697–710. <https://doi.org/10.1111/epi.16099>
29. Consumer Financial Protection Bureau [Internet]. 2024 [cited 2 September 2025]. Measuring financial well-being: A guide to using the CFPB Financial Well-Being Scale. <https://www.consumerfinance.gov/data-research/research-reports/financial-well-being-scale>
30. von Elm E, Altman DG, Egger M, Pocock SJ, Gøtzsche PC, Vandenbroucke JP, et al. The Strengthening the Reporting of Observational Studies in Epidemiology (STROBE) statement: guidelines for reporting observational studies. *J Clin Epidemiol*. 2008 Aug;61(4):344–9. <https://doi.org/10.1016/j.jclinepi.2007.11.008>
31. Chiarotti F, Kodra Y, De Santis M, Bellenghi M, Taruscio D, Carè A, et al. Gender and burden differences in family caregivers of patients affected by ten rare diseases. *Ann Ist Super Sanita*. 2023 Apr-Jun;59(2):122–31. https://doi.org/10.4415/ANN_23_02_05
32. Chu SY, Wen CC, Weng CY. Gender Differences in Caring for Children with Genetic or Rare Diseases: A Mixed-Methods Study. *Children (Basel)*. 2022 Apr;9(5):627. <https://doi.org/10.3390/children9050627>
33. R: The R Project for Statistical Computing [Internet]. [cited 14 September 2025]. <https://www.r-project.org>
34. Yang G, Cintina I, Pariser A, Oehrlein E, Sullivan J, Kennedy A. The national economic burden of rare disease in the United States in 2019. *Orphanet J Rare Dis*. 2022 Apr;17(1):163. <https://doi.org/10.1186/s13023-022-02299-5>
35. Yu J, Chen S, Zhang H, Zhang S, Dong D. Patterns of the Health and Economic Burden of 33 Rare Diseases in China: Nationwide Web-Based Study. *JMIR Public Health Surveill*. 2024 Aug;10:e57353. <https://doi.org/10.2196/57353>
36. Leśniowska J. Economic Burden of Rare Diseases With Common Diseases as a Comorbidity in Poland. *European Management Studies*. 2020;18(89):103–20. <https://doi.org/10.7172/1644-9584.89.6>
37. Kopciuch D, Zaprutko T, Paczkowska A, Nowakowska E. Costs of treatment of adult patients with cystic fibrosis in Poland and internationally. *Public Health*. 2017 Jul;148:49–55. <https://doi.org/10.1016/j.puhe.2017.03.003>
38. Lagae L, Irwin J, Gibson E, Battersby A. Caregiver impact and health service use in high and low severity Dravet syndrome: A multinational cohort study. *Seizure*. 2019 Feb;65:72–9. <https://doi.org/10.1016/j.seizure.2018.12.018>
39. Schreiber-Katz O, Klug C, Thiele S, Schorling E, Zowe J, Reilich P, et al. Comparative cost of illness analysis and assessment of health care burden of Duchenne and Becker muscular dystrophies in Germany. *Orphanet J Rare Dis*. 2014 Dec;9:210. <https://doi.org/10.1186/s13023-014-0210-9>
40. Jarvis J, Chertavian E, Buessing M, Renteria T, Tu L, Hoffer L, et al. The economic impact of caregiving for individuals with Angelman syndrome in the United States: results from a caregiver survey. *Orphanet J Rare Dis*. 2025 Feb;20(1):82. <https://doi.org/10.1186/s13023-025-03551-4>
41. Nabbout R, Dirani M, Teng T, Bianic F, Martin M, Holland R, et al. Impact of childhood Dravet syndrome on care givers of patients with DS, a major impact on mothers. *Epilepsy Behav*. 2020 Jul;108:107094. <https://doi.org/10.1016/j.yebeh.2020.107094>
42. Rodríguez-Santana I, Mestre T, Squitieri F, Willock R, Arnesen A, Clarke A, et al. Economic burden of Huntington disease in Europe and the USA: Results from the Huntington's Disease Burden of Illness study. *Eur J Neurol*. 2023 Apr;30(4):1109–17. <https://doi.org/10.1111/ene.15645>
43. Howat-Rodrigues ABC, Laks J, Marinho V. Translation, cross-cultural adaptation, and psychometric properties of the Brazilian Portuguese version of the Consumer Financial Protection Bureau Financial Well-Being scale. *Trends Psychiatry Psychother*. 2021 Apr-Jun;43(2):134–40. <https://doi.org/10.47626/2237-6089-2020-0034>
44. Evans E, Jacobs M. Diabetes and Financial Well-Being: Differential Hardship Among Vulnerable Populations. *Sci Diabetes Self Manag Care*. 2024 Aug;50(4):263–74. <https://doi.org/10.1177/26350106241256324>
45. Jardaly M, Antoun J, Sakr R, Doumiati H, Shaarani I. Financial Literacy and Wellbeing Among Medical Students, Residents, and Attending Physicians in Lebanon: Results From a Nationwide Multi-Centered Survey. *Inquiry*. 2024 Jan-Dec;61:469580241294135. <https://doi.org/10.1177/00469580241294135>
46. Ellwood S, Weathers J, DeMello J, Graves L, Antoun J, Soares N. Personal Financial Well-being of Family Medicine Residents and Residency Curricula: A CERA Study. *PRiMER*. 2023 Jan;7:415901. <https://doi.org/10.22454/PRiMER.2023.415901>
47. Noronha V, Tongaonkar A, Pillai A, Rao AR, Kumar A, Sehgal A, et al. Prevalence and impact of financial toxicity in older patients with cancer: a prospective observational study in India. *Support Care Cancer*. 2025 Apr;33(5):416. <https://doi.org/10.1007/s00520-025-09252-9>
48. Dosemane D, Khadilkar MN, Kanthila J, Mithra PP. Quality of life and perceived financial implications among otorhinolaryngologists during the COVID-19 pandemic across India. *Acta Otorhinolaryngol Ital*. 2021 Aug;41(4):289–95. <https://doi.org/10.14639/0392-100X-N1229>
49. Huang CHO, Leung RHL, Sit KY, Tsui TYN, Wong JYH, Fung HW. The Financial Well-Being Scale: Reliability, Validity, and Clinical Correlates Among Childhood Trauma Survivors. *Research on Social Work Practice*. 2025;10497315241312889. <https://doi.org/10.1177/10497315241312889>
50. Kempson E, Poppe C. Understanding Financial Well-Being and Capability [Internet]. Høgskolen i Oslo og Akershus; 2018. <https://oda.oslomet.no/oda-xmlui/handle/20.500.12199/5357>