



Testing the validation and reliability of the Caregiver-Patient Activation Measure (CG-PAM)

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ABSTRACT

Objective: The objective of this study was to test the reliability and validity of the Caregiver-Patient Activation Measure (CG-PAM).

Methods: Based on the psychometric testing of the original Patient Activation Measure (PAM), three assessments of reliability and validity were completed on the CG-PAM. Test-retest reliability was assessed across two weeks ($n = 23$). Criterion validity was assessed by interviewing participants from the test-retest cohort ($n = 10$), with transcripts assessed by subject matter experts ($n = 3$) to classify activation levels of the interviewee. Construct validity was assessed through a survey ($n = 179$) consisting of demographic questions, the CG-PAM and concepts hypothesised to be related to caregiver activation.

Results: There was strong test-retest reliability ($r = 0.893$), but poor criterion validity. Assessment of construct validity demonstrated significant relationships found between caregiver activation and weekly hours of care provided ($p < 0.001$), relationship satisfaction ($p < 0.001$), and dyad typology ($p < 0.001$), but not with perceived levels of stress or social support.

Conclusion: The CG-PAM was found to have strong reliability, but there were inconsistent results across the validation tests conducted.

Innovation: Future research must consider the dynamic nature of caring and the importance of the relationship between the caregiver/recipient when defining activation levels within the CG-PAM.

HIGHLIGHTS

- To date, the Caregiver-Patient Activation Measure (CG-PAM) has not been formally tested for reliability or validity
- Methods used were based on the psychometric testing of the original Patient Activation Measure
- The CG-PAM was found to have strong reliability, but there were inconsistent results across the validation tests conducted.
- The dynamic nature of caregiving and the caregiver/receiver relationship are important when conceptualising caregiver activation and how it could be measured.

1. Introduction

Informal caregivers improve the lives of people with chronic illnesses for whom they provide care [1-3]; however, there can be a personal cost of caring. Informal caregivers are known to experience high levels of burden and social isolation, poor physical and mental health outcomes [2-5], and have

the quality of the relationship within their caregiver/receiver (dyad) impacted by caregiving [6]. This dyad, and the way in which it functions, has an important influence on the outcomes of an individual's chronic illness as well as health and wellbeing outcomes of the caregiver [4,7].

With individuals and their informal caregivers self-managing chronic illness in the community [8], there is an increased need to ensure that

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appropriate supports are available for this to occur across the caregiving journey. Informal caregivers have needs around basic self-management knowledge [9], experience a level of uncertainty relating to the implications of the diagnosis, appropriate treatments and help seeking skills [10], and desire improved communication, and the confidence to build improved communication, with health professionals throughout the disease trajectory [10-14]. As such, a better understanding and assessment of informal caregivers' potential to successfully help manage their care recipients' chronic illness is needed.

Patient activation is a commonly used concept throughout the chronic disease self-management literature, and the Patient Activation Measure (PAM) is one of the most widely used measure of activation in both academic and clinical settings [15]. Patient activation is defined as an individual's knowledge, skill, and confidence in managing their own health or chronic condition [8]. Developed by Hibbard and colleagues in the early 2000's, the PAM was originally developed and validated as a 22 item tool [8], with the short version (13 items) developed and validated in 2005 [16]. With questions focussed on such things as knowledge of what prescribed medications do, confidence to independently raise concerns with health professionals and skills to maintain lifestyle changes, the PAM produces a summed and normalised score on a 100-point ordinal scale; assigning activation levels from low (Level 1) to high (Level 4). Low scores typically refer to those patients who are considered passive recipients of health care and are not active patients. Conversely, those at the high end of activation are more proactive about their healthcare needs and are more readily engaged with many preventative health behaviours [17].

Knowing the activation level of an individual can assist health care workers better understand the current capacity and capability of an individual and ensure any treatment or management plans are appropriate to their level of skills, knowledge, and confidence [18]. The PAM can assist both health care workers and individuals to understand their capacity to self-manage their chronic illness(es) [18], but as it is patient-focussed it does not consider the important partnership role informal caregivers have in the self-management process.

Caregivers as well as patients can show different levels of engagement, or activation, with their health treatment. The Caregiver-PAM (CG-PAM) [19] was developed to understand the level of activation in those informal caregivers who play a role in managing the health of the person they care for. The CG-PAM was modelled on the PAM [18], and developed by the same authors. Like the PAM, it is a 13 item tool which addresses the same concepts as the PAM, through almost identical questions but with minor word changes to be from a caregiver perspective, and produces a summed, normalised score out of 100. Like the PAM, a caregiver's activation score can fall within one of four levels with each level providing an indication of where an individual is placed regarding their ability to care for and assist with the management of the care recipient's chronic illness. Caregiving activation and patient activation are likely related but distinct concepts, but this is largely untested. While no formal definition of caregiver activation was established by Hibbard et al., it is used to assess levels of skills, knowledge, and confidence of a caregiver. We employ this operational definition in the present paper.

Despite the large volume of literature that both utilise and validate the PAM, including the translation of the PAM in multiple languages such as German [20], Dutch [21], Spanish [22], and Hebrew [23], there has been minimal published research on the CG-PAM, with some exceptions in the areas of dementia [24], cancer survivorship [25] and stem cell transplants [26]. To the best of the authors' knowledge, there is no peer reviewed empirical data to demonstrate the CG-PAMs validity. Therefore, the purpose of this study was to test the reliability and validity of the CG-PAM with a sample of informal caregivers of people with a chronic illness and a sample of professional experts.

2. Methods

Assessment of the reliability and validity of the CG-PAM was guided by the original psychometric testing process used by the developers of the PAM when the tool was constructed [8]. Our approach included 1. repeated measures survey (test-retest reliability), 2. participant interviews and subject matter expert transcript analysis (criterion validity), and 3. cross-sectional survey (construct validity). By replicating the types of reliability and validity tests conducted by the developers of the PAM, the research procedures followed and, where possible, a replication in sample sizes. This allows a comparison of results, as there is no other CG-PAM validity or reliability study currently published. Some adjustments to variables were required in the construct validity testing to ensure the testing was appropriate for the research population. The University of Canberra (Blinded for Review) Human Research and Ethics Committee approved the study protocol (#20180389 on 20/2/2019).

2.1. Test-retest reliability

2.1.1. Participants

Caregiver participants were recruited through advertisements displayed in the Health Clinics at the University of (Blinded for Review), as well on-line through the distribution channels of jurisdictional peak bodies for various chronic illnesses, such as Parkinson's Disease, Arthritis, and Muscular Dystrophy. Inclusion criteria for all caregiver participants were individuals aged 18 years and over who provide care to another adult who has a long term or chronic illness, can read and speak English, and are able to provide written consent to participate.

2.1.2. Procedure

To assess test-retest reliability, participants were asked to complete the CG-PAM at baseline and again two weeks later. The CG-PAM was administered through the on-line Qualtrics XM platform. Participants were asked to note their favourite colour and sporting team to allow matching of responses from T1 and T2. No other data, such as characteristics of the participant, or their care recipient, were collected.

2.1.3. Data analysis

To assess reliability of the CG-PAM, we used the responses from people who provided data at both T1 and T2 to correlate the scores.

2.2. Criterion validity

2.2.1. Participants

Caregivers for the criterion validity component of the study were recruited from the test-retest participant cohort. Participants who were subject matter experts were recruited through direct contact by the research team leader. Inclusion criteria required experts to be health professionals actively working in the field of caring for people with a chronic illness and their caregivers. All participants received a participant information sheet and provided informed consent.

2.2.2. Procedure

The assessment for criterion validity was two-fold. Initially, 10 participants from the test-retest reliability assessment were invited to participate in a semi-structured one-on-one interview with the research team leader to discuss their caregiving experience. Questions were based on key themes from the CG-PAM including responsibility for caregiving, medication management, and help seeking capabilities. A CG-PAM was administered immediately prior to interview to reflect the participants' current level of activation. Interviews were conducted by telephone with consent from

participants to have the conversations recorded. Interviews varied in length from 25 min to 60 min, and the recordings were transcribed verbatim. Whilst the original validation of the PAM [8] interviewed a total of 10 participants, five from both the highest and lowest PAM scores, this study sought to include participants who also had middle-range scores, in an effort to explore more broadly, caregiving experiences across the range of activation scores.

The second component of the criterion validity assessment was to have the transcripts reviewed by three experts: a general practitioner, an exercise physiologist, and an occupational therapist. Each expert had over 15 years clinical experience, had worked extensively with patients with chronic illness and their informal caregivers, and were registered/accredited with the relevant National Board. Once agreeing to participate each had a meeting the research team leader to discuss the concept of activation prior to assessing the transcripts and classifying each one as fitting into one of the four activation levels. To assist with this, experts were provided with descriptions of activation levels from both the PAM and the CG-PAM (see Table 1). Those provided for the PAM have been well-established, however, this is not the case for the CG-PAM. To date, the only descriptors for CG-PAM activation levels listed in Table 1 derive from research with caregivers of people with dementia [24]. Experts were blinded to the CG-PAM scores of the participants.

2.2.3. Data analysis

In line with the original testing by Hibbard et al. [8], to assess criterion validity, activation scores recorded from each expert were dichotomised to either ‘low’ (activation levels 1 and 2) or ‘high’ (activation levels 3 and 4) for analysis. In addition, unlike the Hibbard et al. study, the initial activation score classification from each expert [1-4] was recorded. Cohen’s kappa was used to assess the caregiver pre-interview activation level and the dichotomised score and the initial activation score from the experts. Analysis was completed using SPSS version 26 and significance levels were set at $p < 0.05$.

2.3. Construct validity

2.3.1. Participants

Caregiver participants for the construct validity component of the study were not part of the test-retest participant cohort. They were recruited through advertisements in in the Health Clinics at the University of (Blinded for Review), as well online through the distribution channels of national peak bodies for various chronic illnesses, such as the Lung Foundation Australia, Heart Support Australia, and Dementia Australia, and through various social media channels. The inclusion criteria for participants were identical to that in Phase 1.

2.3.2. Procedure

To assess the construct validity of the CG-PAM, a survey was conducted using the on-line Qualtrics XM platform. The survey consisted of 43 items including demographic questions ($n = 8$), questions relating to their caregiving (such as the number of hours per week providing care) ($n = 4$), their dyad typology (the way care in managed within their relationship such as caregiver orientated) ($n = 1$), the CG-PAM ($n = 13$). Other items included the ENRICHED Social Support Inventory (ESSI) ($n = 6$), the

Burns Relationship Satisfaction Scale (BRSS) ($n = 7$), and their Perceived Stress and Anxiety Scale (PSS4) ($n = 4$). Higher scores in the CG-PAM, the ESSI, the PSS4 and the BRSS represent higher levels of activation, perceived levels of social support, perceived levels of stress, and relationship satisfaction respectively.

The original PAM used concepts known to be important predictors for successful chronic disease self-management such as physical activity, smoking status, and nutrition [8]. As such, the concepts of social support, relationship quality and perceived stress and anxiety were chosen as suitable predictors of caregiver activation. The literature has also successfully demonstrated the use of these scales when exploring caregiving, chronic disease, and measuring psychosocial wellbeing [27-32]. The scales measuring relationship quality and perceived stress were utilised unchanged. However, the ESSI was adjusted from its original form which contains seven items. In this study, only the five emotional support items of the ESSI were assessed (excluding the question regarding instrumental support as well as the question regarding marital status in the ESSI was removed, as this question was addressed in the demographic component of the survey). This 5 item ESSI scale has been successfully used in previous research with no impact on the scale’s validity [33,34].

2.3.3. Data analysis

Data was entered into SPSS and statistical analysis was completed including independent samples *t*-tests, one-way ANOVAs and correlations – dependent on variable type. The research team became aware during the conduct of this study, that the five item dyad typology originally develop by Buck et al. [35] that was utilised in the survey, had been reviewed and updated to contain four dyad types [36]. Data analyses were therefore conducted using both the original and the contemporary typology. The two typologies yielded very similar results, with the contemporary model selected for inclusion in this paper.

3. Results

3.1. Test-retest reliability

There were 42 participants who initially completed T1, and 23 who completed both T1 and T2. The mean CG-PAM score for T1 was 62.5 ± 13.13 , and for T2 it was 61.35 ± 13.74 ($n = 23$). Pearson’s correlation was $r = 0.893$ ($p = 0.001$, two tailed), suggesting high internal reliability of the instrument. A paired *t*-test showed there was no significant difference between T1 and T2 scores.

3.2. Criterion validity

The pre-interview CG-PAM score, the associated activation level [1-4] and dichotomised activation level (high/low) was recorded for each participant (see Table 2). Of the 10 transcripts reviewed and assigned an activation level by the experts, there was only one occasion where all three provided an identical score (Participant #9). Interestingly, their assessment matched the participant’s pre-interview activation level. Cohen’s kappa showed there was no agreement between participant pre-interview and expert classification of activation levels.

Table 1
Descriptors and scores of the four activation levels for the PAM and the CG-PAM.

	PAM [15]	Caregiver PAM [24]
Level 1 Score 0–47	Individuals are passive and lack confidence. Knowledge is low, goal-orientation is weak, and adherence is poor	May not yet believe that they play a role in managing the patient’s health –they may not believe their role is important
Level 2 Score 47–55.1	Individuals have some knowledge, but large gaps remain. They believe health is largely out of their control, but can set simple goals	Lacks confidence and knowledge to take action on behalf of the patient
Level 3 Score 55.2–72.4	Individuals have the key facts and are building self-management skills. They strive for best practice behaviours, and are goal-oriented	The caregiver is beginning to take action and feel confident they are in charge
Level 4 Score 72.5–100	Individuals have adopted new behaviours, but may struggle in times of stress or change. Maintaining a healthy lifestyle is a key focus	The caregiver is confident, but may have difficulty maintaining their level of involvement over time

Table 2
CG-PAM Assessment Outcomes from the Criterion Validity Analysis.

Participant ID	Pre-Interview CG-PAM Score	Pre-Interview CG-PAM Level*	Expert #1 Assessment	Expert #2 Assessment	Expert #3 Assessment
1	45.3	1	4	3	3
2	47.0	1	2	2	4
3	55.6	3	3	4	4
4	55.6	3	3	4	2
5	58.1	3	4	4	3
6	65.5	3	2	3	2
7	67.8	3	3	4	3
8	77.7	4	3	4	4
9	77.7	4	4	4	4
10	84.84	4	4	4	3

* Activation levels 1 and 2 represent 'Low Activation', levels 3 and 4 represent 'High Activation'.

Analysis of the dichotomised high/low activation levels demonstrated agreement between the experts on six occasions, again with the agreed level of the experts matching the pre-interview activation level of that participant. Cohen's kappa showed only one expert demonstrated a moderate agreement with the pre-interview dichotomised activation levels ($k = 0.615, p = 0.035$).

3.3. Construct validity

Of the 193 who commenced the survey, 179 completed all items. Of the 193 participants (all of whom completed the demographics questions), the majority were female, aged over 45 years, married, tertiary-educated, Christian, born in Australia, and spoke only English at home (see Table 3). Most participants were the spouse/partner of the person they provide care for, with almost half of participants stating they spend over 31 h a week providing care.

The results from the CG PAM and the three instruments used to assess caregiver wellbeing can be found in Table 4, along with the means (M) and standard deviations (SD) of each instrument as well as the score range for each. The internal-consistency reliability scores for each scale using Cronbach's alpha are recorded, with all internal reliability scores are above 0.78, suggesting good to high levels of internal reliability. Additionally, for each instrument, no items detracted from their scale's

Table 3
Characteristics of participants.

Characteristic	n = 193
Gender, female, n (%)	166 (85.6%)
Age (years), n (%)	
25-34	9 (4.7%)
35-44	23 (11.9%)
45-54	44 (22.8%)
55-64	54 (28.0%)
65-74	45 (23.3%)
75+	17 (8.8%)
Married, n (%)	128 (66.0%)
Education (tertiary education beyond high school)	158 (81.4%)
Religion	
Christian	85 (43.8%)
No religion	77 (39.7%)
Country of birth, Australia, n (%)	138 (77.1%)
Speaks only English at home, n (%)	174 (90.2%)
Relationship with care recipient, n (%)	
Spouse/partner	85 (43.8%)
Parent	50 (25.8%)
Child	30 (15.5%)
Hours of caregiving per week*, n (%)	
Less than 15	60 (31.4%)
15-30	46 (24.1%)
31+	85 (44.5%)

* Hours of care were recorded as individual hours but collapsed to three categories for summary reporting.

reliability and removing items would not improve the Cronbach's alpha for that instrument.

There were no significant differences on CG-PAM scores due to gender, marital status, education, religious affiliation, relationship-type between caregiver and care recipient, or levels of social support (ESSI). The relationship between CG-PAM scores and perceived levels of stress (PSS4) approached significance ($r = -0.138, n = 183, p = 0.062$, two tailed).

CG-PAM scores differed significantly by age, weekly hours of care provide, relationship satisfaction (BRSS), and dyad type. With respect to age, there was a significant difference between CG-PAM scores and age groups, $F = 2.449, p = 0.035, \eta_p^2 = 0.062$. A Tukey post hoc test revealed that participants aged 65-74 years had significantly higher caregiver activation scores (66.97 ± 11.57) than participants aged 55-64 years (58.81 ± 13.87). There were no other significant differences reported between groups.

There was a significant positive correlation between CG-PAM scores and hours of care provided each week, $r = 0.262, n = 191, p < 0.001$, two tailed - indicating that those with higher caregiver activation scores also provided more hours of care each week. There was a significant positive correlation between CG-PAM scores and relationship satisfaction, $r = 0.254, n = 179, p = 0.001$, two tailed - indicating that those with higher caregiver activation scores were more likely to have increased relationship satisfaction.

Using the contemporary dyad typology where caregivers were either classified as being patient orientated, carer orientated, collaborative or incongruent, there was a significant difference between CG-PAM scores and dyad type as determined by one-way ANOVA ($F = 13.659, p < 0.001, \eta_p^2 = 0.181$). A Tukey post hoc test revealed that dyads that were caregiver orientated had significantly higher CG-PAM scores (68.9 ± 14.88) than dyads that were patient orientated ($51.28 \pm 10.47, p < 0.001$) and those that were incongruent ($53.40 \pm 10.82, p < 0.001$). Dyads that were collaborative had significantly higher CG-PAM scores (63.79 ± 13.07) than dyads that were patient orientated ($p < 0.001$) and those that were incongruent ($p = 0.001$). There were no other significant differences between groups.

4. Discussion and conclusion

4.1. Discussion

This study aimed to validate the CG-PAM utilising a range of methods guided by the validation of the original 22-item PAM. We found high levels of internal reliability, however, there were inconsistent results in both the criterion and construct validity components of the study.

The PAM has been validated many times using a range of methods, in different languages, and has good to high levels of test re-test reliability [37] across a range of populations [38-40]. In the PAM for Adolescents, tested and validated in Germany, the test re-test reliability was $r = 0.68 (p < 0.01)$ [41], whereas the test re-test reliability score during the development of the PAM for Mental Health was $r = 0.74$ (p not reported) [42]. Examining other caregiver activation measures, only the validation study of the Partnering for Better Health - Living with Chronic Illness: Dementia reported a test re-test reliability of $r = 0.76$ [43]. It is therefore possible to say that the CG-PAM has high internal reliability when compared to other test re-test reliability measures from a range of PAM validation studies and other caregiver activation studies.

Cohen's kappa test demonstrated that there was no agreement between experts and the pre-interview CG-PAM activation levels and demonstrated a moderate agreement with pre-interview activation levels were dichotomised to high and low. This suggests there is limited criterion validity for the CG-PAM in this study. This result is in direct contrast to the original validation of the PAM [8]. There are several plausible explanations for this. Firstly, the limited numbers ($n = 10$) of participant scores rated by the experts, although in line with the original validation paper by Hibbard et al. [8], does limit the reliability of the results. Secondly, the descriptors of what activation levels 1-4 look like for a caregiver as provided to the

Table 4
Descriptive analysis of instrument scores.

Instrument and number of items	Total Participants	M ± SD	Score Range	Possible Score Range	Internal Consistency
CGPAM (n = 13)	n = 193	61.43 ± 14.09	31.70–100.00	0–100	α = 0.84
ESSI (n = 5)	n = 188	14.02 ± 5.20	5–25	5–25	α = 0.92
PSS4 (n = 4)	n = 183	7.84 ± 2.92	2–16	0–16	α = 0.78
BRSS (n = 7)	n = 179	25.01 ± 11.69	0–42	0–42	α = 0.94

Caregiver Patient Activation Measure (CG-PAM), ENRICHED Social Support Inventory (ESSI), Perceived Stress and Anxiety Scale (PSS4), Burns Relationship Satisfaction Scale (BRSS).

experts (see Table 1) may lack accuracy. Descriptors provided were limited, reflecting the current literature, suggesting that the original PAM descriptors may not be directly transferrable to a caregiver perspective, and that the initial work completed by Parker [24] whilst promising, needs to be developed further. Thirdly, the variability of the experts regarding their clinical experience and relationships with people who have chronic conditions, and their caregivers, could have had an impact on their interpretation of both the narrative in the transcript and how they applied the descriptors of the activation levels.

Construct validity was tested to explore the relationship between caregiver activation and caregiver characteristics, which included a range of demographic variables as well as measures hypothesised to be predictors of activation based on the literature. In this study, the scales measuring social support, perceived stress and anxiety and relationship satisfaction represented the true test of construct validity of these CG-PAM and its relationship to these concepts, and the results were varied. As with previous PAM research, this study demonstrated that there was so significant difference between activation scores and most demographics [17,44]. As expected, our study found a positive relationship between CG-PAM scores and relationship quality. The relationship with the person they care for intrinsically shapes the way in which a caregiver responds to, and interprets, the demands of caregiving [45]. As such, the importance of relationship quality on the impact on the caregivers' health and wellbeing has been well documented in the literature and is consistent across a broad range of chronic conditions, as the strain of chronic disease can impact on relationship quality [46].

Relationship quality affects caregiver outcomes [6] and those that report high relationship quality are: less likely to experience caregiver burden [47–50]; have more caregiver satisfaction and wellbeing [47,48]; more likely to be able to buffer the strain of caregiving [51] and better cope with stress [52]. Importantly, studies have demonstrated that the effect of relationship quality was consistent, even when controlling for socioeconomic variables [47,48], highlighting the significant impact relationship quality has on caregiver outcomes. These positive outcomes for caregivers associated with positive relationship quality are reflective of outcomes that would be associated with an individual who was highly activated. PAM studies have demonstrated that those who are more highly activated are more likely to have better health outcomes [53], lower depression scores higher quality of life scores [54,55], and higher levels of self-efficacy [56]. It is therefore possible to state that the CG-PAM performed as expected when tested against relationship quality.

Relationship quality cannot be examined independently from the concept of the caregiver/receiver dyad. Utilizing the dyad typology developed by Buck and colleagues [36], this study found that caregiver activation was significantly associated with two key dyad types, caregiver-centred, and those that were collaborative. It is possible that the former can be explained through the fundamental ideals of activation – skills, knowledge and confidence. If a caregiver self nominates their dyad typology as caregiver-oriented (“I take care of most their care needs without input from them”) then as the core provider of care, particularly as this often happens towards the end of the disease trajectory [35], it is not surprising that over time, they have developed that level of activation. This is supported by the positive and significant correlation found in this survey between CG-PAM scores and hours spent caring. The second dyad typology that demonstrated significantly higher CG-PAM scores was that of collaboratively orientated. As this classification is founded on communication and relationships

[35], it too, was expected to have a positive association with activation, noting the importance of relationship quality in the dyad.

What was unexpected in the results was that there was no significant association between CG-PAM scores and either perceived stress and anxiety or social support. With PAM studies demonstrating that individuals with higher activation had lower depression scores [54] and understanding stress and anxiety are pertinent caregiver characteristics [43], it was anticipated that a significant association would be found. As the PSS4 is a small-scale instrument it may not have been able to fully address perceived levels of stress compared to larger scales. However, given that the results were approaching significance, and were significant at a one tailed calculation, sample size may be the more appropriate explanation as to why the expected relationship wasn't found.

Social support has been identified as a significant self-need for caregivers [57] and can be provided through both formal and informal relationships [58]. Caregivers of people with chronic illnesses rely on their own social network for support, with caregivers perceiving greater social support from friends and significant others (compared to family) [59]. Support can be considered as either perceived or received [45,58,60]. It has been shown that perceived social support can buffer the negative impact on caregiving stressors [45], mediate association between resilience and caregiver burden [58], and it has been demonstrated that the effect size in subjective burden larger when the social support is perceived [60]. It is possible that a significant relationship between CG-PAM scores and social support does exist but wasn't found in this study due to either the sample size, or the tool used in the survey to measure social support.

Like the PAM, the CG-PAM is a scale intended to be universal. Knowing the level of activation of caregivers may be a useful tool to understand the level of assistance needed to undertake this care. However, as a one-off measure, the CG-PAM is only able to provide a snapshot of the caregiver's current state and is unable to contextualise the dynamic experience of caregiving that fluctuates with the needs of both the caregiver and the care recipient [61]. This was demonstrated within the results of the criterion study. Participant 1 received an activation score of 45.3 – placing her in the lowest activation level of 1, however, all three experts rated her as highly activated. Her interview demonstrated proactive behaviours, the provision of high levels of emotional support to both the care recipient and immediate family members, and confidence and ability to manage relationships both internal and external to the family – all of which would suggest high levels of activation. However, as these behaviours are not focussed on clinical or physical care provision, they are missed by the CG-PAM, nor are they addressed in the descriptions of each of the caregiver activation levels. It would be valuable for future research on caregiver activation to investigate the inclusion of the emotional and supportive aspects of care provision, how caregiving changes over time, and the context in which the care is provided. This would then allow the CG-PAM to be used in a practical setting to communicate to both dyad members how to develop a healthy care relationship that would benefit both members.

One of the key limitations for this study is the lack of an operational definition of ‘caregiver activation’ from the developers as there is for patient activation. However, the key constructs of skills, knowledge and confidence are assessed in the CG-PAM as they are in the PAM. As such, the authors are confident that the operational definition utilised throughout this paper is faithful to the original concept of activation as developed by Hibbard et al. Other limitations include the participant numbers in the test re-test

study and the larger survey. Additionally, except for age, there was a distinct level of homogeneity in the participant sample which does have implications for the generalisability of the results to a broader, more diverse population. This study also relied on caregiver participants being recruited through either a health facility or through a relevant peak organisation. This gives way to potential bias of caregiver participants who are engaged in a level of support. Finally, the shortage of literature that has reported validity or reliability data for the CG-PAM resulted in limited opportunities to compare results.

4.2. Innovation

This research took an important step forward in the validation of the CG-PAM, addressing a research gap that exists in this area. The literature demonstrates the high value the PAM has for patients, clinicians, and researchers to understand patient activation levels and how this can be used to improve patient outcomes [18,53,62]. As such, the CG-PAM also has potential to be an important instrument to better understand caregiver activation. Results of this study demonstrate that the skills, confidence, and knowledge an individual has related to the physical or clinical tasks of caregiving, are significantly related to the time someone spends caring and both the quality of the relationship and the way care is provided or managed within the dyad. This is an important finding that adds critical information to future development of the caregiver-PAM and the understanding of how it can be utilised in both research and clinical settings.

4.3. Conclusion

There were mixed results across the various reliability and validation tests conducted, as well as no significant relationship with two concepts that the literature has shown are important in the caregiving space – social support, and perceived stress and anxiety. However, as expected from the literature, significant relationships were found between caregivers with high activation and high relationship quality scores, as well as those who identified their dyad typology as either caregiver orientated or collaborative.

Due to the modest use of CG-PAM in the caregiving literature to date, the concepts and constructs of what each activation level means and how it represents the situation of caregiver, requires further exploration and development before this measure can be confidently utilised to assist caregivers in practice. As highlighted in this research, the importance of relationship quality and the typology of the caregiver/receiver dyad, suggests that these concepts should also be included in any future research on both caregiver activation and caregiver wellbeing.

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Declaration of Competing Interest

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Appendix A. Supplementary data

Supplementary data to this article can be found online at <https://doi.org/10.1016/j.pecinn.2022.100098>.

References

- [1] Riyahi A, Abdolrazzagi H, Sarlak N, Faraji S, Nobakht Z. Comparison of time-use patterns and self-efficacy in family caregivers of patients with chronic disease. *Int J Ther Rehabil*. 2020;27(12):1–10.
- [2] Noonan MC, Wingham J, Taylor RS. 'Who Cares?' The experiences of caregivers of adults living with heart failure, chronic obstructive pulmonary disease and coronary artery disease: a mixed methods systematic review. *BMJ Open*. 2018;8(7):e020927.
- [3] Schulman-Green D, Feder SL, Dionne-Odom JN, Batten J, En Long VJ, Harris Y, et al. Family caregiver support of patient self-management during chronic, life-limiting illness: a qualitative metasynthesis. *J Fam Nurs*. 2020;1074840720977180.
- [4] Iovino P, Lyons KS, De Maria M, Vellone E, Ausili D, Lee CS, et al. Patient and caregiver contributions to self-care in multiple chronic conditions: A multilevel modelling analysis. *Int J Nurs Stud*. 2020;103574.
- [5] Faronbi JO, Faronbi GO, Ayamolowo SJ, Olaogun AA. Caring for the seniors with chronic illness: The lived experience of caregivers of older adults. *Arch Gerontol Geriatr*. 2019;82:8–14.
- [6] Park EO, Schumacher KL. The state of the science of family caregiver-care receiver mutuality: a systematic review. *Nurs Inq*. 2014;21(2):140–52.
- [7] Badr H, Acitelli LK. Re-thinking dyadic coping in the context of chronic illness. *Curr Opin Psychol*. 2017;13:44–8.
- [8] Hibbard JH, Stockard J, Mahoney ER, Tusler M. Development of the Patient Activation Measure (PAM): Conceptualizing and Measuring Activation in Patients and Consumers. *Health Serv Res*. 2004;39(4, Part 1):22.
- [9] Clark AM, Spaling M, Harkness K, Spiers J, Strachan PH, Thompson DR, et al. Determinants of effective heart failure self-care: a systematic review of patients' and caregivers' perceptions. *Heart*. 2014;100(9):716–21.
- [10] Browne S, Macdonald S, May CR, Macleod U, Mair FS. Patient, carer and professional perspectives on barriers and facilitators to quality care in advanced heart failure. *PLoS One*. 2014;9(3):e93288.
- [11] Burke RE, Jones J, Ho PM, Bekelman DB. Caregivers' perceived roles in caring for patients with heart failure: what do clinicians need to know? *J Card Fail*. 2014;20(10):731–8.
- [12] Doherty LC, Fitzsimons D, McIlpatrick SJ. Carers' needs in advanced heart failure: A systematic narrative review. *Eur J Cardiovasc Nurs*. 2016;15(4):203–12.
- [13] Holden RJ, Schubert CC, Mickelson RS. The patient work system: An analysis of self-care performance barriers among elderly heart failure patients and their informal caregivers. *Appl Ergon*. 2015;47:133–50.
- [14] Cameron J, Rhodes KL, Ski CF, Thompson DR. Carers' views on patient self-care in chronic heart failure. *J Clin Nurs*. 2016;25(1–2):144–52.
- [15] Insignia Health. Patient Activation Measure (PAM): Insignia Health. [Available from: <https://www.insigniahealth.com/>; 2018.
- [16] Hibbard JH, Mahoney ER, Stockard J, Tusler M. Development and testing of a short form of the patient activation measure. *Health Serv Res*. 2005;40(6 Pt 1):1918–30.
- [17] Greene J, Hibbard JH. Why does patient activation matter? An examination of the relationships between patient activation and health-related outcomes. *J Gen Intern Med*. 2011;27(5):520–6.
- [18] Hibbard JH, Greene J, Tusler M. Improving the outcomes of disease management by tailoring care to the patient's level of activation. *Am J Manag Care*. 2009;15(6):353–60.
- [19] Insignia Health. Caregiver/Carer Patient Activation Measure (CG-PAM) 13 UK. University of Oregon; 2015. [Available from: https://solihulltogether.co.uk/images/Patient_Activation/UK_Carer_PAM_13.pdf.
- [20] Kvrjic S, Beck E-M, Cavelti M, Kossowsky J, Stieglitz R-D, Vauth R. Focusing on the adult attachment style in schizophrenia in community mental health centres: validation of the Psychosis Attachment Measure (PAM) in a German-speaking sample. *Int J Soc Psychiatry*. 2012;58(4):362–73.
- [21] Rademakers J, Nijman J, van der Hoek L, Heijmans M, Rijken M. Measuring patient activation in The Netherlands: translation and validation of the American short form Patient Activation Measure (PAM13). *BMC Public Health*. 2012;12(1):1–7.
- [22] Moreno-Chico C, González-de Paz L, Monforte-Royo C, Arrighi E, Navarro-Rubio MD, Gallart Fernández-Puebla A. Adaptation to European Spanish and psychometric properties of the patient activation measure 13 in patients with chronic diseases. *Fam Pract*. 2017;34(5):627–34.
- [23] Magnezi R, Glasser S. Psychometric properties of the hebrew translation of the patient activation measure (PAM-13). *PLoS One*. 2014;9(11):e113391.
- [24] Parker TR. Influence of Caregiver Activation on Health of Informal Caregivers of persons with Alzheimer's. Newberg, Oregon: George Fox University; 2015.
- [25] Mazanec SR, Sattar A, Delaney CP, Daly BJ. Activation for health management in colorectal cancer survivors and their family caregivers. *West J Nurs Res*. 2016;38(3):325–44.
- [26] Fauer AJ, Hoodin F, Lalonde L, Erickson J, Runaas L, Churay T, et al. Impact of a health information technology tool addressing information needs of caregivers of adult and pediatric hematopoietic stem cell transplantation patients. *Support Care Cancer*. 2019;27(6):2103–12.
- [27] Witt D, Benson G, Campbell S, Sillah A, Berra K. Measures of patient activation and social support in a peer-led support network for women with cardiovascular disease. *J Cardiopulm Rehabil Prev*. 2016;36(6):430–7.
- [28] Vaglio J, Conard M, Poston WS, O'Keefe J, Haddock CK, House J, et al. Testing the performance of the ENRICH social support instrument in cardiac patients. *Health Qual Life Outcomes*. 2004;2(1):1.
- [29] Wolever RQ, Webber DM, Meunier JP, Greeson JM, Lausier ER, Gaudet TW. Modifiable disease risk, readiness to change, and psychosocial functioning improve with integrative medicine immersion model. *Altern Ther Health Med*. 2011;17(4):38.
- [30] Steadman PL, Tremont G, Davis JD. Premorbid relationship satisfaction and caregiver burden in dementia caregivers. *J Geriatr Psychiatry Neurol*. 2007;20(2):115–9.

- [31] Warttig SL, Forshaw MJ, South J, White AK. New, normative, English-sample data for the Short Form Perceived Stress Scale (PSS-4). *J Health Psychol*. 2013;18(12):1617–28.
- [32] Buck H, McMillan S, Zambroski C. “Everything they were discussing, we were already doing”: hospice heart failure caregivers respond to a caregiving intervention (SA507-A). *J Pain Symptom Manage*. 2013;45(2):397.
- [33] Barry LC, Kasl SV, Lichtman J, Vaccarino V, Krumholz HM. Social support and change in health-related quality of life 6 months after coronary artery bypass grafting. *J Psychosom Res*. 2006;60(2):185–93.
- [34] Bucholz EM, Strait KM, Dreyer RP, Geda M, Spatz ES, Bueno H, et al. Effect of low perceived social support on health outcomes in young patients with acute myocardial infarction: results from the variation in recovery: role of gender on outcomes of young AMI patients (VIRGO) study. *J Am Heart Assoc*. 2014;3(5):e001252.
- [35] Buck HG, Kitko L, Hupcey JE. Dyadic heart failure care types: qualitative evidence for a novel typology. *J Cardiovasc Nurs*. 2013;28(6):37–46.
- [36] Buck HG, Hupcey J, Juárez-Vela R, Vellone E, Riegel B. Heart failure care dyadic typology: initial conceptualization, advances in thinking, and future directions of a clinically relevant classification system. *J Cardiovasc Nurs*. 2019;34(2):159.
- [37] Skolasky RL, Green AF, Scharfstein D, Boulton C, Reider L, Wegener ST. Psychometric properties of the patient activation measure among multimorbid older adults. *Health Serv Res*. 2011;46(2):457–78.
- [38] Skolasky RL, Mackenzie EJ, Riley LH, Wegener ST. Psychometric properties of the Patient Activation Measure among individuals presenting for elective lumbar spine surgery. *Qual Life Res*. 2009;18(10):1357–66.
- [39] Moljord IEO, Lara-Cabrera ML, Perestelo-Pérez L, Rivero-Santana A, Eriksen L, Linaker OM. Psychometric properties of the Patient Activation Measure-13 among out-patients waiting for mental health treatment: A validation study in Norway. *Patient Educ Couns*. 2015;98(11):1410–7.
- [40] Melby K, Nygård M, Brobakken MF, Gråwe RW, Güzey IC, Reitan SK, et al. Test-retest reliability of the patient activation measure-13 in adults with substance use disorders and schizophrenia spectrum disorders. *Int J Environ Res Public Health*. 2021;18(3):1185.
- [41] Bomba F, Markwart H, Mühlen H, Menrath I, Ernst G, Thyen U, et al. Adaptation and validation of the German Patient Activation Measure for adolescents with chronic conditions in transitional care: PAM@ 13 for Adolescents. *Res Nurs Health*. 2018;41(1):78–87.
- [42] Green CA, Perrin NA, Polen MR, Leo MC, Hibbard JH, Tusler M. Development of the patient activation measure for mental health. *Adm Policy Ment Health*. 2010;37(4):327–33.
- [43] Sadak T, Korpak A, Borson S. Measuring caregiver activation for health care: Validation of PBH-LCI-D. *Geriatr Nurs*. 2015;36(4):284–92.
- [44] Skolasky RL, Mackenzie EJ, Wegener ST, Riley III LH. Patient activation and adherence to physical therapy in persons undergoing spine surgery. *Spine*. 2008;33(21):E784.
- [45] Cooney TM, Proulx CM, Bekelman DB. Changes in social support and relational mutuality as moderators in the association between heart failure patient functioning and caregiver burden. *J Cardiovasc Nurs*. 2020;26(3):212–20. <https://doi.org/10.1097/JCN.0000000000000726>.
- [46] Meier C, Bodenmann G, Mörgeli H, Jenewein J. Dyadic coping, quality of life, and psychological distress among chronic obstructive pulmonary disease patients and their partners. *Int J Chron Obstruct Pulmon Dis*. 2011;6:583.
- [47] Tough H, Brinkhof MW, Siegrist J, Fekete C. Subjective caregiver burden and caregiver satisfaction: the role of partner relationship quality and reciprocity. *Arch Phys Med Rehabil*. 2017;98(10):2042–51.
- [48] Rippon I, Quinn C, Martyr A, Morris R, Nelis SM, Jones IR, et al. The impact of relationship quality on life satisfaction and well-being in dementia caregiving dyads: findings from the IDEAL study; 2019.
- [49] Lum HD, Lo D, Hooker S, Bekelman DB. Caregiving in heart failure: Relationship quality is associated with caregiver benefit finding and caregiver burden. *Heart Lung: J Acute Critical Care*. 2014;43(4):306–10.
- [50] Hooker SA, Grigsby ME, Riegel B, Bekelman DB. The impact of relationship quality on health-related outcomes in heart failure patients and informal family caregivers: an integrative review. *J Cardiovasc Nurs*. 2015;30(4S):S52–63.
- [51] Solomon DN, Hansen L, Baggs JG, Lyons KS. Relationship quality in non-cognitively impaired mother–daughter care dyads: A systematic review. *J Fam Nurs*. 2015;21(4):551–78.
- [52] McPheters JK, Sandberg JG. The relationship among couple relationship quality, physical functioning, and depression in multiple sclerosis patients and partners. *Fam Syst Health*. 2010;28(1):48.
- [53] Hibbard JH, Greene J. What the evidence shows about patient activation: better health outcomes and care experiences; fewer data on costs. *Health Aff (Millwood)*. 2013;32(2):207–14.
- [54] Magnezi R, Glasser S, Shalev H, Sheiber A, Reuveni H. Patient activation, depression and quality of life. *Patient Educ Couns*. 2014;94(3):432–7.
- [55] Prey JE, Qian M, Restaino S, Hibbard J, Bakken S, Schnall R, et al. Reliability and validity of the patient activation measure in hospitalized patients. *Patient Educ Couns*. 2016;99(12):2026–33.
- [56] Fortin PR, Da Costa D, Neville C, Julien A-S, Rahme E, Haroun V, Singer W, Nimigon-Young J, Morrison A-L, Eng D, Peschken CA, Vinet E, Hudson M, Smith D, Matsos M, Pope JE, Clarke AE, Keeling S, Avina-Zubieta JA, Rochon M. Challenges of Perceived Self-Management in Lupus. *Arthritis Care Res*. 2022;74:1113–21. <https://doi-org.ezproxy.canberra.edu.au/10.1002/acr.24542>.
- [57] Sabo K, Chin E. Self-care needs and practices for the older adult caregiver: An integrative review. *Geriatr Nurs*. 2021;42(2):570–81. <https://doi.org/10.1016/j.gerinurse.2020.10.013>.
- [58] Ong HL, Vaingankar JA, Abidin E, Sambasivam R, Fauziana R, Tan M-E, et al. Resilience and burden in caregivers of older adults: moderating and mediating effects of perceived social support. *BMC Psychiatry*. 2018;18(1):1–9.
- [59] De Maria M, Tagliabue S, Ausili D, Vellone E, Matarese M. Perceived social support and health-related quality of life in older adults who have multiple chronic conditions and their caregivers: a dyadic analysis. *Soc Sci Med*. 2020;262:113193.
- [60] Del-Pino-Casado R, Frías-Osuna A, Palomino-Moral PA, Ruzafa-Martínez M, Ramos-Morcillo AJ. Social support and subjective burden in caregivers of adults and older adults: A meta-analysis. *PLoS One*. 2018;13(1):e0189874.
- [61] Ambrosio L, Navarta-Sánchez MV, Carvajal A, Garcia-Vivar C. Living with chronic illness from the family perspective: an integrative review. *Clin Nurs Res*. 2021;30(5):579–90.
- [62] Dixon A, Hibbard J, Tusler M. How do people with different levels of activation self-manage their chronic conditions? *Patient*. 2009;2(4):257–68.