Most common refusals of personal care in advanced dementia: psychometric properties of the RoCIS

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Abstract

Background and Objectives: Refusals of care in dementia can be a source of distress for people with dementia and their caregivers. Informant-based measures to examine refusals of care are limited and often measure other behaviours such as agitation. We aimed to assess the validity and reliability of the newly developed, 14-item, Refusals of Care Informant Scale (RoCIS) and then use the scale to verify the most common refusal behaviours.

Research Design and Methods: Data from 129 dyads were analysed. Dyad was defined as a person with advanced dementia either living in a care home or supported in their own home and their caregiver. Data about the person with dementia were gathered using informant-based questionnaires. The psychometric properties of the RoCIS were investigated using Rasch analysis to determine validity and reliability.

Results: Following Rasch analysis, the item 'upset' was removed from the RoCIS. The reduced 13-item RoCIS is unidimensional and achieved a reliability index of 0.85 (Cronbach's alpha 0.88). 68% of people with dementia had refused care in the last month, with 'verbally refused' the most common type of refusal behaviour. People in the 'very severe/profound' stage of dementia showed more refusal behaviours than those in the 'severe' stage.

Discussion and Implications: Results provide initial evidence that the RoCIS is a valid and reliable informant-based scale measuring refusals of care in advanced dementia. Results indicate a need to develop new approaches and techniques to make assistance with personal care more acceptable to people with dementia.

Background and Objectives

Over 58 million people are living with dementia globally (Alzheimer's Disease International et al., 2020). The term dementia refers to a range of progressive neurological conditions (Alzheimer's Disease being the most common subtype), which encompass a series of cognitive symptoms affecting memory, communication, thinking, and judgement, often accompanied by changes in mood, behaviour and motivation (World Health Organisation, 2021). As dementia advances people living with it require physical assistance with their personal care such as with bathing, dressing, and going to the toilet (Giebel et al, 2014).

Sometimes people who are experiencing advanced stages of dementia find assistance with their care unacceptable and refuse it (Ishii et al., 2012). Refusals of care in dementia are often understandable actions from a person with dementia when their caregiver (family carers or care-home staff in this research) attempts to assist them with a personal care activity. Refusals can be related to the caregiver approach such as if they outpace the person (Hallberg et al, 1995) or use elderspeak (a patronising, overly simple communication style) (Williams et al, 2017); unmet needs such as the person being hungry, thirsty, or uncomfortable (Ishii et al., 2012); the person not recognising the caregiver or understanding the caregiver's intentions (Volicer, 2021), or being in pain, depressed or having psychotic symptoms such as hallucinations or delusions (Galindo-Garre et al., 2015; Ishii et al., 2010). A person with dementia can refuse or indicate their dissatisfaction with the care provided in many ways, including moving away, ignoring the caregiver, verbally refusing, or becoming upset or aggressive (Mahoney et al, 1999; Volicer and Hurley, 2015).

Whatever the cause/s of a particular refusal of care, prolonged uncompleted care could lead to poor hygiene, soreness, infection, and could constitute neglect (Backhouse, 2021).

Distressing situations are likely to impact negatively on a person with dementia and their caregiver's daily lives, making refusals of care in dementia important targets for intervention (Fauth, Femia and Zarit, 2016; Ishii, Streim and Saliba, 2012).

Reducing refusals of care

Relational approaches and interventions aimed at caregivers could prevent or reduce refusals (Volicer, 2021). Several caregiving interventions have been developed to prevent or reduce refusals of care (Backhouse et al, 2020). Currently, evidence on different bathing techniques such as thermal baths or strip washes and playing recorded music during care (Backhouse et al, 2020), is the strongest in reducing refusals of care. These interventions aim to make the care interaction more acceptable and pleasant for people with dementia by adjusting the sensory experience of the care.

Measuring refusals of care

Measures of refusals of care, and interactions leading to these, are necessary to evaluate a person with dementia's experiences of care interactions, difficulties within care interactions, or the effectiveness of caregiver interventions to reduce refusals occurring. People in the later stages of dementia are less able to articulate their experiences and often unable to provide information about themselves. Therefore, to gain insight into the lives of people with advanced dementia researchers and clinicians turn to informants, often the person's caregiver. Informant-based measures can be useful to elicit caregivers' perspectives of people with dementia's actions.

In the past, studies have framed refusals as agitation and used informant-based agitation scales such as the Cohen Mansfield Agitation Inventory (Cohen-Mansfield, 1986) (for

example, Hicks-Moore 2005) or the Pittsburgh Agitation Scale (Rosen et al, 1994) (for example, Sidani et al, 2011) as an indicator of refusals of care. However, refusals of care are different to general agitation and aggression, since the former always occur within an interaction as a response to caregiver communication or actions (Volicer, 2021; Volicer, Bass and Luther, 2007), therefore, it is likely these scales do not accurately measure refusals of care.

Many other existing measures include a refusal of care component within a scale measuring behaviour more generally (Choi et al, 2020; Galik et al, 2017). For example, one study isolated six items from the 44-item Weekly Recording of Behaviour scale (Son et al, 2007) to examine refusals of care through informant-based responses (Fauth, Femia and Zarit, 2015); some of these questions arguably did not measure refusals of care, such as with the item 'wore inappropriate clothes.'

The Resistiveness-to-Care Dementia of Alzheimer's Type (RTC-DAT) scale is a specific refusal of care measure (Mahoney et al, 1999; Volicer and Hurley, 2015). It is a 13-item observational scale, often used to score video-recorded care interactions, measuring the frequency and duration of a range of refusal behaviours. This measure has been validated using Rasch analysis (Galik et al, 2017) and is particularly suitable for use with people in the advanced stages of dementia (Volicer and van der Steen, 2014). Since observational research takes considerable time resources, access to research settings can be complex, and it is not always acceptable or practical to observe personal care interactions there is a clear need for an informant-based measure of refusals of care. A suitable refusal of care informant-based scale was not found in the literature; therefore, we used the RTC-DAT as a starting point to develop one.

The purpose of the new scale was to record if different refusal behaviours were present or absent over the last month, identifying types of behaviour that occurred. A total score of refusal behaviours is created by adding all items, which describes the magnitude of refusal behaviours that occurred in the same period. RoCIS can be used as an outcome measure, and also aid in care planning therefore enabling future targeted intervention development.

Scale development

Drawing on the hitherto most comprehensive delineation of refusals of care; the RTC-DAT (Mahoney et al, 1999; Volicer and Hurley, 2015), we developed an informant-based measure to assess whether and which refusal of care reactions had occurred in the last month. In meetings with lay research advisors (around a table to discuss ideas with two family carers and in separate individual meetings with two care-home staff, all of whom were assisting people with dementia) and individual meetings with two expert colleagues we assessed items from the RTC-DAT for ease of caregiver identification, recognition and answering and explored whether other refusal behaviours also occurred. Our lay research advisors suggested they had experienced non-response/ignoring and not physically co-operating as refusal behaviours, so these were added to our scale. Table 1 shows the Refusal of Care Informant Scale (RoCIS) items aligned with corresponding RTC-DAT items. Since the RoCIS is an informant measure, it asks whether each refusal behaviour has occurred during personal care interactions over the last month.

We adopted the assumption that all refusal behaviours would be part of a single construct "refusals of care", with the RoCIS identifying the type of refusal behaviours occurring and the total score indicating the magnitude of refusals of care. We hypothesised that (a) different refusal behaviours (scale items) would represent different levels of complexity in refusals,

with actions becoming less socially complex, (b) dementia severity would influence the type of refusal behaviours that occur (for example, more non-verbal and aggressive behaviours used by those more impaired), and (c) that RoCIS scores would be positively associated with agitation and negatively associated with ADL function.

Objectives

To evaluate the validity and reliability of the Refusal of Care Informant Scale (RoCIS) and then use the scale to verify the most common refusal behaviours using a sample of people with advanced dementia.

Research Design and Methods

A Rasch analysis was employed to document and evaluate the measurement functioning of different refusal of care behaviours for people with dementia on the RoCIS (Boone, 2016). Rasch analysis is appropriate when the total score of a questionnaire stems from its items summed together (Tennant and Conaghan, 2007). Rasch analysis plots the difficulty of each scale item along a linear continuum, with some items being milder (easier) for people with dementia to enact and some more intense (difficult), and considers the ability of each respondent (Linacre, 2021). We used Rasch analysis to enable learning about the intensity of different refusal behaviours (Boone, 2016).

Design and sample

Data for this study were derived from the Pro-CARE study, funded by the Alzheimer's Society, UK, a cross-sectional study which aimed to determine the factors associated with refusals of care in dementia. The RoCIS was developed to be the main outcome variable for the Pro-CARE study.

Participants

A sample of 130 dyads (n=260 participants) were recruited in England (Jan/2019-May/2021) comprising 106 dyads of people supported at home with a family carer, and 24 dyads of care-home residents with a care-home staff member, from eight care homes. Both participant types were included to allow learning from each setting and determine during the Pro-CARE study whether caregiver status influenced different refusal behaviours. Care homes in England provide 24-hour accommodation and personal care through qualified nursing or care without qualified nursing. One dyad had to withdraw from the study due to family circumstances before data for the RoCIS were collected, therefore data on n=129 dyads were used in this analysis.

People with dementia were eligible to participate if they were aged 65 or over, had advanced dementia and were receiving physical support with their personal care; dementia stage eligibility was assessed after consent using the Frontier Dementia Rating Scale (Mioshi et al., 2010). Family carers and care-home staff (henceforward collectively termed as caregivers) were eligible to participate if they were physically assisting the person with advanced dementia with their personal care. Other eligibility criteria included: care-home staff had assisted the person with dementia with their personal care eight times over the previous month, and family carers were the primary family carer. Caregivers were informants about the person with dementia they were supporting.

Ethical approval was granted from the Queen's Square Research Ethics Committee, London, UK [Reference:251339]. Written and verbal information was provided to all caregivers and to people with dementia where appropriate. In line with the Mental Capacity Act (2005) of England and Wales, where a person with dementia was assessed as not having the capacity

to make the research decision at that time, assent from them was sought if appropriate, and a close family member or friend who knew the person well was consulted about whether they thought the person would have been likely to have wanted to take part had they have had capacity to make the decision. Written consent was obtained for all participants.

Procedure

All data collection was conducted by the first author, who has prior experience of working in care homes, liaising with family carers and assisting people with dementia with their personal care. Study measures were informant-based assessments filled in by the first author from face-to-face (n=73), telephone (n=41) and online (n=15) interviews with caregivers.

Measures

Demographic details were taken including age, gender, ethnicity and living situation.

Data on the following scales were collected.

The **Cohen Mansfield Agitation Inventory (CMAI)** is a 29-item agitation measure including items such as screaming, biting and pushing, each scored 1-7 to indicate frequency of behaviour (total score range: 29-203). Higher scores indicate more agitation occurring in the previous two weeks (Cohen-Mansfield, 1986).

The **Alzheimer's Disease Co-operative Study Activities of Daily Living Inventory Severe Impairment Version (ADCS-ADL-Sev 19)** is a 19-item questionnaire assessing activities of daily living such as grooming, bathing, and going out (total score range: 0-54). Higher scores indicate greater function with activities of daily living (Galasko et al., 2005; Galesko et al., 1997).

The **Frontier Dementia Rating Scale (FRS)**, a well-validated, 30-item dementia severity staging tool assessing functional aspects of daily life for example, self-care, behaviour, and household chores (Mioshi et al., 2010). Total score is the percentage of applicable scores where no change in function was present compared to a participant's pre-morbid function. Percentage scores are translated to logit scores for analysis. Lower scores indicate greater dementia severity (Mioshi et al., 2010).

The newly developed **RoCIS**, a 14-item scale asking whether particular refusal behaviours such as clamped jaw, not physically co-operate, and pushed caregiver away had occurred in the last month. Summative scores range between 0-14. Higher scores indicate more types of refusal behaviours had occurred.

Data Analyses

Descriptive statistics (n, percentage for categorical data and mean, standard deviation for continuous data), Cronbach's alpha and correlations were calculated in STATA/MP17.0 (STATA/MP, 2021). To evaluate validity and reliability of the RoCIS, Rasch analyses using the WINSTEPS statistical program version 5.1.4 (Linacre, 2015) were performed. The Rasch model is well known as the standard for modern psychometric evaluations (Tennant and Conaghan, 2007).

Separation and reliability indexes

Item separation verifies the item spread and item reliability verifies confidence in the replicability of the item difficulty hierarchy with other samples (Bond and Fox, 2015). A separation index of 3.0 and reliability of 0.9 reflects very good confirmation of the item level difficulty hierarchy (Linacre, 2021). If item separation and reliability values are below the

recommended levels a larger sample may be needed to confirm the item difficulty hierarchy (Linacre, 2021; Boone, Staver and Yale, 2014).

Item fit

Item fit was examined using infit and outfit statistics, to determine how well each item fits the Rasch model and to detect problem items. Mean square fit statistics show the size of misfit in the data (Bond and Fox, 2015). Mean squares were examined for both infit and outfit statistics, values between 0.6 and 1.4 are considered productive for measurement for rating scale data (Wright and Linacre, 1994; Bond and Fox, 2015), Z distributions of mean squares should be between 2.00 and -2.00, outside of this range means items have significantly less compatibility with the model (Bond and Fox, 2015). Items outside the specified parameters should be assessed for possible removal from the scale targeting higher outfit items first (Boone, Staver and Yale, 2014).

Unidimensionality

Item polarity uses the point-measure correlation (PTMEA-Corr), to assess dimensionality and determine if responses to each item align with the overall construct. PTMEA-Corr statistics should be positive and not close to zero to show that they are consistent with the underlying construct – refusals of care (Bond and Fox, 2015). A principal component analysis (PCA) of the residuals from Rasch analysis was performed to assure the scale was measuring one construct only – refusals of care; eigenvalues up to 2.0 are confirmatory (Linacre, 2021).

Item mapping of difficulty

Wright maps plot persons and items along the Rasch unidimensional logit scale showing item difficulty (in relation to refusals of care: milder to more intense behaviours) and person ability,

also denoting the mean and standard deviation of each (Boone, Staver and Yale, 2014). A Wright map was used to assess distribution and location of items and to identify gaps where more items may be needed.

Differential Item Functioning (DIF)

DIF was examined for two-sub-groups: gender (male and female) and participant type (care-home resident or person supported at home). To learn more about the scale, DIF was used to determine if each item had the same intensity (difficulty) for both groups. DIF was defined using 1) the Rasch-Welch (logistic regression) t-test: this estimates a Rasch difficulty for each item for each person group, a significance of p ≤0.05 was used (Boone, Staver and Yale, 2014).

Convergent validity

Convergent validity was assessed to determine if there were relationships between refusals of care (RoCIS) and agitation (CMAI) using bivariate correlation with a significance cut off level of P ≤0.05. We hypothesised that higher agitation levels would correlate with higher refusal of care scores on the RoCIS.

Results

Table 2 shows the characteristics of the people with dementia and their caregivers. People with dementia were on average 80 years old, 52% male, mostly married or with a partner (74%), and predominantly White (97%). Caregivers were 65 years old on average, 71% female, mostly spouses or care workers, predominantly White 96% and had on average been caring for the person with dementia 5 years. All participants with dementia scored severe (n=92), very severe (n=35) or profound (n=2) on the FRS, with a mean of severe (range -6.66 to -0.4, mean -2.27, SD:1.19). Due to low sample size (n=2), the *profound* category was combined

with the *very severe* category for analysis. People with dementia were reported as having moderate to severe functional dependence with 67% of participants scoring 27/54 or less on the ADCS-ADL-Sev (range 0-46, mean 20.31, SD:12.58), and showing minimal agitation (CMAI range 29-85, mean 43.92, SD:13.34).

Adapting the RoCIS

An initial Rasch analysis showed that the mean squares of infit and outfit statistics for most items were within the recommended range (0.6–1.4). However, two items, 'upset' and 'verbally refused', had mean squares over 1.4 for outfit and infit and Z scores over 2.0 (See Supplementary Material Table A) indicating too much variation in the responses and that these items had less compatibility with the model. When the most misfitting item, 'upset', was removed, the whole model item separation and reliability increased from 2.22 and 0.83 to 2.39 and 0.85 respectively. When 'upset' and 'verbally refused' were both removed from the model, whole model item separation and reliability dropped to 1.62 and 0.72 respectively. Due to this drop in whole model reliability, and after considering the items from a clinical perspective, we decided to remove only 'upset' from the RoCIS. The following analyses and results refer to the reduced 13-item RoCIS after the item 'upset' was removed.

Separation and reliability indexes

For the reduced 13-item RoCIS whole model real item separation was 2.39 (more than two levels of separation) and item reliability was 0.85, which are acceptable, but indicate a larger sample size may be needed in future to confirm the item difficulty hierarchy. Cronbach's alpha coefficient was 0.88, which was within the optimal range (Streiner and Norman, 2003).

Item fit

Table 3 shows the infit and outfit statistics. The mean squares of fit statistics for all items were found to be within the recommended range (0.6–1.4), except 'verbally refused', which has a mean square of 1.58 for outfit and 2.45 for infit and Z scores over 2.0 indicating more variation than that would be ideal in the responses for this item and less compatibility with the model. 'Verbally refused' should be a target for improvement in the future.

Unidimensionality

Table 3 shows the PTMEA Corr values for each item in the RoCIS, all are well over zero scoring 0.52 and over (range 0.52-0.71). These scores, typically termed as item-total correlation in classical test theory, indicate the correlation between the item score and the overall assessment score. In our results, all items being over 0.5 indicates very good discrimination; referring to how well each item differentiates between participants who refuse and those that do not refuse. PCA showed that eigenvalues for the five principal components of Rasch residuals ranged from 2.10 to 1.18 which indicates no obvious deviation from unidimensionality. Results seem to confirm that the RoCIS scale measures 'refusals of care' as one single construct, as hypothesised.

Item mapping

Item mapping order is shown in Figure 1. 'Verbally refused' was the easiest refusal behaviour demonstrated by the person with dementia and detected by the scale; 'physical aggression' the most intense. There was a large gap in logits between the easiest item 'verbally refused' (-1.94) and the second easiest item 'verbally aggressive' (-53), indicating the addition of more easy items may benefit the scale.

Differential Item Functioning

DIF was assessed for gender and participant type (care-home resident and person supported at home). There were statistically significant differences for gender for two items: 'moved away' (*P*=0.04) showing this item was less likely from males and 'clamped jaw' (*P*=0.02) showing this item was less likely from females. There was a statistically significant difference for participant type for one item: 'unresponsive' (*P*=0.03) showing this item was less likely from care-home residents.

Convergent validity

People with dementia who were more agitated on the CMAI demonstrated more refusals of care (r= 0.55, P<0.01) and those with greater ability with ADLs demonstrated less refusals of care (r= -0.46, P<0.01). Therefore, higher agitation levels were correlated to more refusal behaviours and greater function with ADLs to less refusal behaviours.

Are there differences in refusals of care by dementia severity?

We used the newly validated 13-item RoCIS to determine the number of refusal behaviours and frequency of different refusals of care in relation to dementia severity in our sample. Sixty eight percent of participants (88/129) had refused care in the last month (range 0-13, mean 2.97, SD:3.44). Table 4 shows summary statistics; people with *very severe/profound* dementia demonstrated the highest number of different refusal behaviours (mean 5.46; SD:3.45) compared to those with *severe* (mean 1.98; SD:2.91), with over 75% in the *very severe/profound* stage demonstrating three or more different refusal behaviours (see supplementary material Table B). Figure 3 shows the distribution of the overall RoCIS score by dementia severity.

Overall, 384 refusal behaviours were reported. As shown in Table 5, 'Verbally refused' was the most common refusal behaviour (44.2% of participants), with 'verbally aggressive' (27.9%) and gripped on to items (27.1%) the next two most common. Figure 2 shows the percentage of different refusal behaviours ordered from milder to more intense by dementia stage. Milder behaviours were most common for those with *severe* dementia, whereas people with *very severe/profound* dementia demonstrated behaviours more evenly across the range of intensities.

Discussion and Implications

The RoCIS was developed to provide a much-needed informant-based measure of refusals of care in advanced dementia. This article has described the development and content of the RoCIS and provided initial evidence for its validity and reliability while also verifying the most common refusal behaviours in a sample of care-home residents and people supported at home living with advanced dementia. One item 'upset' was removed from the 14-item RoCIS due to misfitting the Rasch model. The remaining 13-item RoCIS showed good reliability and validity for measuring "refusals of care" in advanced dementia. Analyses of unidimensionality suggested that the 13 refusal behaviours were part of a single construct "refusals of care". The RoCIS is likely to be useful for measuring the magnitude of refusals of care in research and clinical settings.

The significant correlation between agitation behaviours on the CMAI and refusals of care demonstrates convergent validity, supports our hypothesis, and aligns with previous research showing people with dementia who experience agitation are likely to also refuse care (Galik et al, 2017; Kable et al., 2012). However, the correlation was not so high as to indicate refusals of care are the same as agitation, indeed they have different causes, with refusals being

relational and created within interactions (Volicer, 2021), and they require different interventions (Kable et al., 2012). Additionally, the negative correlation with ADL function indicates a link between refusals and functional impairment, with higher support needs linked to more refusals.

Differences in item functioning were found for three items. These items could have been considered for deletion, however the individual items fit the Rasch model and in our view their deletion would have reduced the clinical applicability of the scale. Care-home residents were less likely to be 'unresponsive' than people supported at home. This could be due to personal relationships between family members being closer or taken for granted, meaning ignoring a person is easier for people supported at home than in social or formal relationships, which would be found in care-home settings. Rasch items are rated by level of difficulty and analysis showed females found 'clamped jaw' more intense, and males found 'moved away' more intense, which could be linked to males being more likely to engage in physically combative situations than females (Björkqvist, 2018).

The results seem to confirm our hypothesis that different refusal behaviours (scale items) would represent different levels of complexity in refusals, with actions becoming less socially complex. This was indicated by 'verbally refused' and 'verbally aggressive' being the mildest items for people with dementia to demonstrate and also the most socially complex to enact requiring verbal abilities. Whereas more intense refusal behaviours such as 'not physically co-operate' and 'physically aggressive' were the most intense to demonstrate and less socially complex, making use of the physical body to demonstrate refusal.

Our results provide some support for our hypothesis that dementia severity would influence the type of refusal behaviours that occur. Our data showed that people with *very*

severe/profound dementia were more likely to use a range of intensities of refusal behaviours including more intense refusal behaviours (physical movements) than those with *severe* dementia who predominantly used 'verbally refused'. Social complexity may be relevant here due to people with *very severe/profound* dementia having lower ability to articulate their feelings verbally meaning they may resort to more physical refusals. Alternatively, it could indicate that people with dementia who are more impaired become angrier and more physical, perhaps due to not understanding caregivers' intentions.

A Rasch analysis of the RTC-DAT observational scale (Galik et al, 2017), which informed the development of the RoCIS, found 'cry' and 'say no' to be easier items in the scale and while fitting the model they had the highest mean square scores for outfit and infit. These items underpinned the RoCIS items 'upset' and 'verbally refused' which were the most misfitting items in our Rasch analysis. Clinically, 'upset' can be viewed as a way for the person to show the caregiver that they are not happy with the care being conducted but may not be a refusal. 'Verbally refused' is an important refusal behaviour as a way for people with dementia to refuse without being combative such as with pushing equipment away or not physically co-operating. In this way 'verbally refused' can be viewed as a more socially acceptable mode of refusing. Analysis showed more easy items would enhance the scale and 'verbally refused' was the easiest refusal behaviour for people with dementia to demonstrate, so was important to retain. However, the RoCIS does not enable us to determine whether people with dementia who verbally refused did so before care commenced or during care interactions.

Measuring refusal behaviours will allow the type of behaviours caregivers are encountering to be determined and enable the development of targeted interventions for adapting caregiver approaches and making care more acceptable to the person with dementia. The

RoCIS allows a snapshot of refusals over the last month to be obtained quickly and easily by researchers and clinicians enabling knowledge of the scale of the phenomenon to be gained and clinical advice to be tailored to particular modes of refusal.

Strengths and limitations

The RoCIS is an informant-based measure, therefore responses relied on caregivers' interpretations of the questions and their interpretation of which behaviours by people with dementia were categorised as refusals. Informant-based scales may elicit biased answers, especially if the caregiver has been rejected (and perhaps insulted) by the person with dementia. Assessing interrater reliability from more than one caregiver per person with dementia would have strengthened the results. The instrument development stage could have involved further consultations and used formal methods. The sample included people from two key settings of dementia care allowing learning about both settings, however, there were less data from care-home settings. A larger sample may have increased item separation and reliability index scores. Still, the RoCIS is the first informant-based scale to support assessment of refusals of behaviour in advanced dementia. It is easy and quick to complete, and cost-effective as it is a paper questionnaire.

Conclusions

This study provides initial evidence that the RoCIS is a reliable and valid scale for use with caregivers of people living with advanced dementia. The RoCIS provides an essential informant-based measure of refusals of care for use in research and clinical settings. Future work could consider: 1) adapting the item 'verbally refused' for better fit, since the relatively extreme statistics for this item could indicate a second dimension, and 2) adding more refusal behaviours to the scale which are easy for people with dementia to demonstrate. Refusals of

care are most common in the *very severe/profound* stage, with verbal refusals the most common mode of refusal overall. There is a need to develop new approaches and techniques to make assistance with personal care more acceptable to people with dementia. The RoCIS is free for academic use and available from the corresponding author.

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TABLE/FIGURE LEGENDS:

TABLE 1: REFUSAL OF CARE INFORMANT SCALE ITEMS ALIGNED WITH RTC-DAT ITEMS

TABLE 2: PARTICIPANT CHARACTERISTICS

TABLE 3: REFUSAL OF CARE INFORMANT SCALE (ROCIS) ITEM STATISTICS IN ORDER OF FIT

TABLE 4: SUMMARY STATISTICS OF THE ROCIS BY DEMENTIA SEVERITY

TABLE 5: ITEMS REPORTED n(%) BY DEMENTIA SEVERITY

FIGURE 1: REFUSAL BEHAVIOURS IN ORDER OF DIFFICULTY SHOWING LOGITS AND POSITIONING ON SCALE

FIGURE 2: REFUSAL BEHAVIOURS REPORTED BY DEMENTIA STAGE ORDERED FROM THE MILDEST TO THE MORE INTENSE ITEMS

FIGURE 3: BOXPLOT OF THE OVERALL ROCIS SCORE DISTRIBUTION BY DEMENTIA SEVERITY

Table 1: Refusal of Care Informant Scale items aligned with RTC-DAT items

RTC-DAT Items n=13	Refusal of Care Informant Scale Items n=14	Shortened item description used in this article
Turn away Pull away	Person leaned, moved, or looked away from caregiver	Moved away
Push away	Person pushed caregiver away	Pushed caregiver away
	Person pushed care equipment away	Pushed care equipment away
Push/ Pull	Person tugged at things (e.g., towel, caregiver's clothes)	Tugged items
Grab object	Person gripped on to items (e.g., clothes, covers, towel, toothbrush)	Gripped on to items
Grab person	Person gripped on to caregiver	Gripped on to caregiver
Adduct	Person stiffened their body	Stiffened body
Hit/ Kick	Person was physically aggressive (e.g., nipped, pushed, slapped, spat at, hurt caregiver)	Physically aggressive
Say no	Person verbally refused (declined to co-operate)	Verbally refused
Cry	Person was visibly upset during care	*Upset
Threaten Scream/ Yell	Person was verbally aggressive (e.g., shouted, shrieked)	Verbally aggressive
Clench mouth	Person clamped their jaw	Clamped jaw
No equivalent item	Person became unresponsive (e.g., ignored caregivers attempts to provide assistance)	Unresponsive
No equivalent item	Person would not physically co-operate (e.g., Person made themselves heavy, stood or leant forward)	Not physically co-operate

*Upset item deleted for the final scale

Table 2: Participant Characteristics

Variable (Range)	Mean (SD)	Frequency (%)
Person with dementia		**n=129**
Age in years (65-99)	80.28 (7.95)	
Gender		
Males		67 (51.9)
Females		62 (48.1)
Marital status		
Married / with Partner		96 (74.4)
Widowed		26 (20.2)
Single		3 (2.3)
Divorced		4 (3.1)
Ethnicity		
White		125 (96.9)
Black		1 (0.8)
Asian		2 (1.6)
Mixed		1 (0.8)
Dementia severity		
Severe		92 (71.3)
Very severe		35 (27.1)
Profound		2 (1.6)
FRS (5.39 to -6.66)	-2.27 (1.19)	
CMAI (29 to 203) n=128	43.92 (13.34)	
ADCS-ADL-Sev19 (0 to 54) n=128	20.31 (12.58)	
Caregiver		**n=129**
Age in years (19-87)	64.9 (16.40)	
Gender		
Males		37 (28.7)
Females		92 (71.3)
Ethnicity n=128		
White		123 (96.1)
Black		2 (1.6)
Asian		3 (2.3)
Caregiver relationship to person with dementia		
Spouse/partner		85 (65.9)
Child		15 (11.6)
Other family member		3 (2.3)
Friend		2 (1.6)
Care worker		17 (13.2)
Senior care worker		7 (5.4)
Length of time caring for the person with dementia in years (0.5-20)	5.26 (3.45)	

FRS: Frontier Dementia Rating Scale; CMAI: Cohen Mansfield Agitation Inventory; ADCS-ADL-Sev 19: Alzheimer's Disease Co-operative Study Activities of Daily Living Inventory Severe Impairment Version

Table 3: Refusal of Care Informant Scale (RoCIS) item statistics in order of fit

	INFIT		OUTFIT		Item mapping order	PTMEA Corr / item validity
ITEM	mnsq	ZSTD	mnsq	ZSTD	1=mildest	
Verbally refused	1.58	4.37	2.45	3.61	1	0.52
Clamped jaw	1.27	1.74	1.34	1.24	8	0.53
Unresponsive	1.13	0.98	1.27	1.23	4	0.61
Moved away	1.20	1.39	1.25	1.11	5	0.59
Physically aggressive	0.98	-0.05	0.72	-0.58	13	0.57
Pushed care equipment away	0.95	-0.30	0.87	-0.37	9	0.63
Verbally aggressive	0.94	-0.42	0.83	-0.78	2	0.68
Gripped on to caregiver	0.92	-0.57	0.86	-0.55	6	0.66
Gripped on to items	0.83	-1.31	0.72	-1.41	3	0.71
Not physically co-operate	0.80	-1.08	0.51	-1.27	12	0.62
Tugged items	0.78	-1.29	0.49	-1.54	11	0.64
Stiffened body	0.77	-1.55	0.52	-1.84	10	0.68
Pushed caregiver away	0.76	-1.83	0.68	-1.44	7	0.71

mnsq: mean square; PTMEA Corr: point-measure correlation

Table 4: Summary statistics of the RoCIS by dementia severity

	Descriptive Statistics of overall RoCIS score			
Dementia severity	Mean	SD	Skewness	Kurtosis
Severe	1.98	2.91	1.84	5.62
Very severe/profound	5.46	3.45	0.35	2.32

Table 5: Items reported n(%) by dementia severity

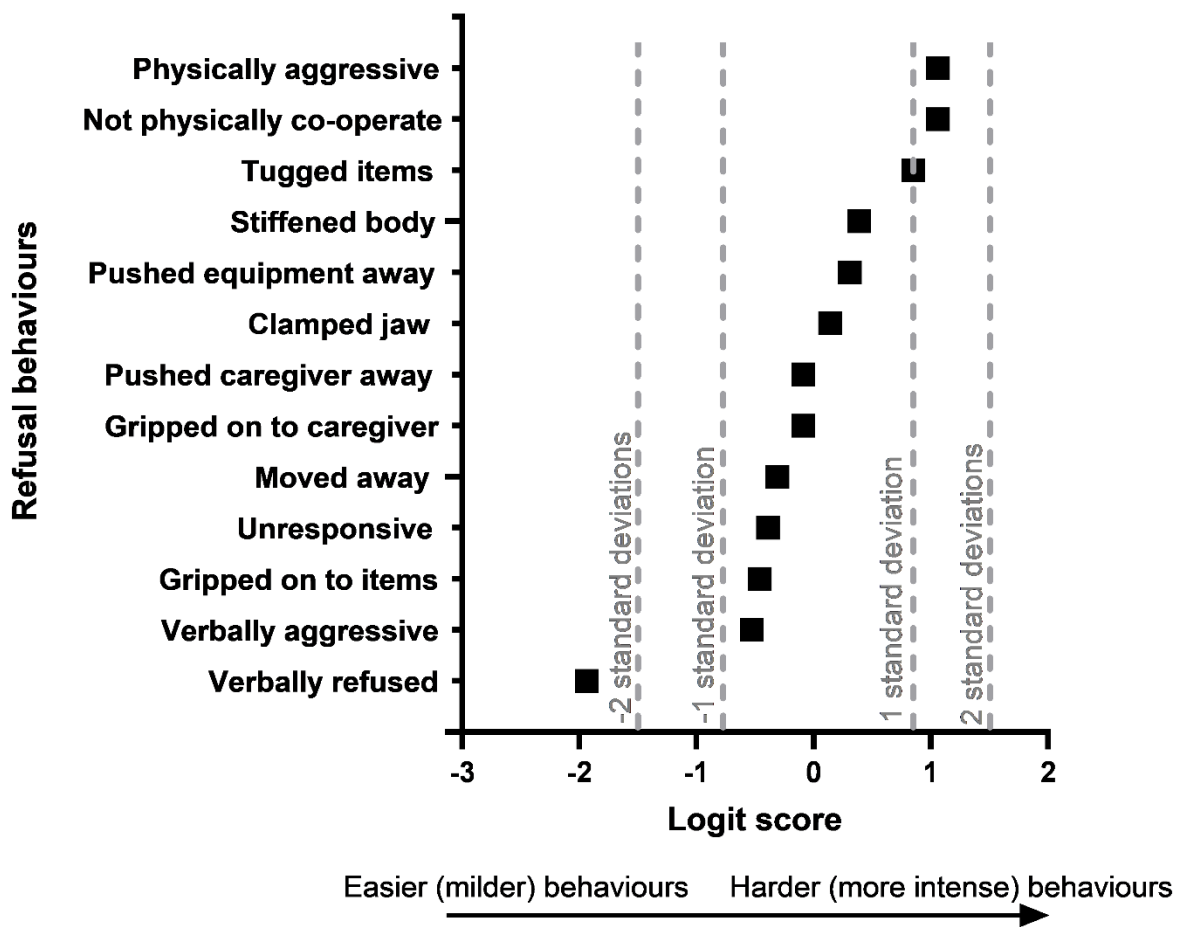| ITEM	Total caregivers reporting item n=129 n(%)	Severe n=92 n(%)	Very severe/ Profound n=37 n(%)
Verbally refused	57 (44.2)	42 (45.7)	15 (40.5)
Verbally aggressive	36 (27.9)	19 (20.7)	17 (45.9)
Gripped on to items	35 (27.1)	13 (14.1)	22 (59.5)
Unresponsive	34 (26.4)	17 (18.5)	17 (45.9)
Moved away	33 (25.6)	20 (21.7)	13 (35.1)
Gripped on to caregiver	30 (23.3)	11 (12.0)	19 (51.4)
Pushed caregiver away	30 (23.3)	13 (14.1)	17 (45.9)
Clamped jaw	27 (20.9)	10 (10.9)	17 (45.9)
Pushed care equipment away	25 (19.4)	10 (10.9)	15 (40.5)
Stiffened body	24 (18.6)	8 (8.7)	16 (43.2)
Tugged items	19 (14.7)	6 (6.5)	13 (35.1)
Not physically co-operate	17 (13.2)	8 (8.7)	9 (24.3)
Physically aggressive	17 (13.2)	5 (5.4)	12 (32.4)

Figure 1: Refusal behaviours in order of difficulty showing logits and positioning on scale
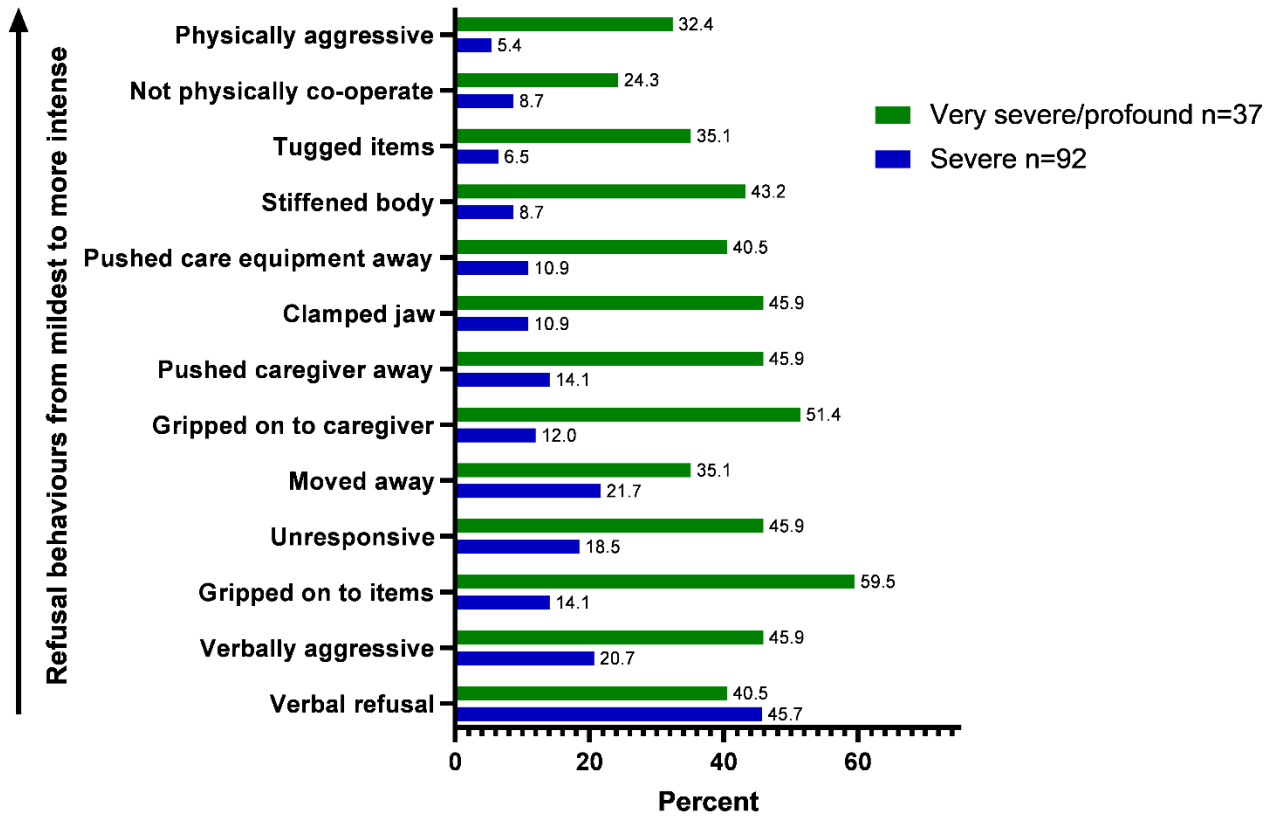
Figure 2: Refusal behaviours reported by dementia stage ordered from the mildest to the more intense items
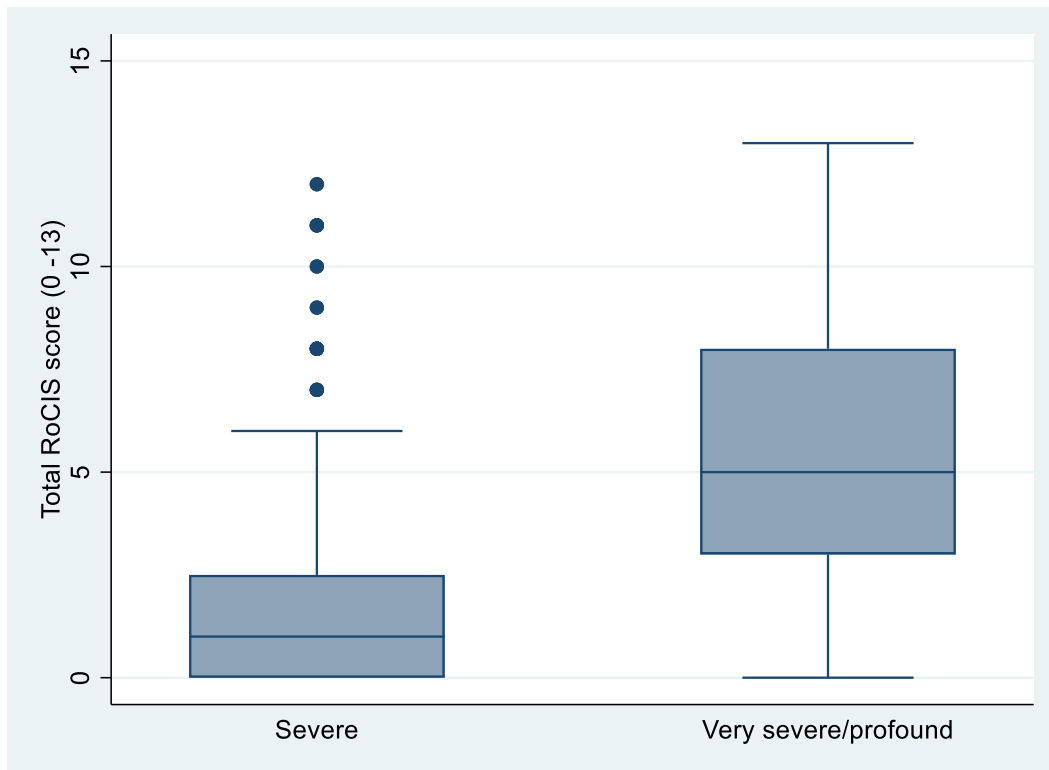
Figure 3: boxplot of the overall RoCIS score distribution by dementia severity