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Title: Development and pilot testing of the revised Patients' Attitudes Towards Deprescribing questionnaire for people with cognitive impairment

Abstract

Objectives: 1) To develop a version of the revised Patients' Attitude Towards Deprescribing (rPATD) questionnaire for people with mild cognitive impairment and mild-to-moderate dementia (rPATDcog) and 2) capture the beliefs and attitudes of this population and their carers about deprescribing through a pilot study.

Methods: Firstly, the rPATDcog was modified from the rPATD and tested in a small group of participants with mild cognitive impairment, then we conducted a pilot study of the rPATDcog and the carers' rPATD.

Results: Twenty-one participants with cognitive impairment and 11 carer participants (forming dyads) participated in this study. Eighty-one percent (17/21) of participants said that they would stop one or more of their medications if their doctor said it was possible. There was excellent agreement of corresponding questions between dyads.

Conclusions: The rPATDcog was feasible to administer in this study. Further work is required to provide generalisable results and determine utility in practice.

Key words

Deprescription; dementia; caregivers; polypharmacy

Introduction

There is a high prevalence of potentially inappropriate medication use among people with dementia [1]. In addition to appropriate prescribing of new medications, regular assessment of the continuing need of a medication as well as its potential for harm is required; that is, identification and deprescription of inappropriate medications [2]. Deprescribing is complex in people with dementia due to limited evidence on the benefits/harms and pharmacokinetics/pharmcodynamics of medications in this population, difficulties establishing goals of care and the involvement of family members/carers in decision making [2,3].

With the view of delivering patient-centred care, and the knowledge that general practitioners often cite individuals and/or family members as a barrier to deprescribing [4], a questionnaire was previously developed and validated which quantitatively captures values and attitudes towards deprescribing. The revised Patients' Attitudes Towards Deprescribing (rPATD) questionnaire has two versions: one for older adults and one for carers of older adults [5]. People with mild cognitive impairment (MCI) and mild to moderate dementia may still be involved in decision making regarding their medications [6]. It is not yet known if their preferences will be different to that of the general population, but, it is important to be able to elicit their views and beliefs about their medications and deprescribing.

The aim of this study was to develop a version of the rPATD suitable for people with MCI and mild to moderate dementia. Additionally, we aimed to conduct a pilot study to capture the views and beliefs of people with MCI and mild to moderate dementia and their carers regarding deprescribing.

Methods

Ethical approval for this study was granted by the Northern Sydney Local Health District Human Research Ethics Committee, Australia (LNR/16/HAWKE/216).

Participants

Participants were recruited through an aged care outpatient department at a tertiary referral teaching hospital. The two types of participants in this study were participants with cognitive impairment and carer participants. Individuals were eligible for inclusion if they/their care recipient had a diagnosis of MCI or mild to moderate dementia and they/their care recipient was taking at least one regular prescription medication. Diagnosis was determined by a geriatrician or referring GP (including type of dementia) and/or Mini-Mental State Exam (mild dementia 21-26, moderate dementia 10-20) or equivalent Rowland Universal Dementia

Assessment Scale (RUDAS) [7], as documented in case notes. All participants had to be 18 years or older and able to communicate in or understand English and carer participants had to also be able to complete a written questionnaire in English.

Design and data collection

The study contained two phases: the adaptation phase and the data collection phase.

Adaptation phase

The recently validated rPATD for older adults [5] was used to develop a questionnaire for people with cognitive impairment (see Box, Appendix I). The questionnaire was designed to be administered by a researcher or a health care professional (unlike the rPATD which was developed for self-administration).

In the adaptation phase, the modified questionnaire was administered by one of the members of the research team and the understanding of the person with cognitive impairment was ascertained via targeted and open questions during and after completion of the questionnaire (cognitive interview technique) [8]. Necessary changes to the wording of the questionnaire were conducted iteratively until a final version was considered appropriate (hereafter called the rPATDcog). No carers were recruited for the adaptation phase.

Data collection phase

The data collection phase involved participation from both the person with cognitive impairment and their carer. Where there was no carer present (or carer did not consent to participation) the person with cognitive impairment was still invited to participate. After obtaining consent, the researcher administered the rPATDcog to the participant with cognitive impairment, while the carer participant was given the carers rPATD questionnaire to self-complete.

Participant characteristics, medical conditions, medications, medication management practices and goals of care were collected from case notes and/or through interview.

Analysis

The data collection phase was a pilot study. Descriptive statistics were used to present the results. Cohen's kappa coefficient was used to measure the agreement between the views of people with cognitive impairment with those of their carers. This analysis was undertaken in Microsoft Excel (version number 15.26 (160910), Australia). As this was a development and pilot study no sample size calculation was conducted. For the adaption phase, recruitment was continued until the questionnaire was considered appropriate for moving into the data collection phase.

Results

Adaptation phase

The questionnaire was tested in five participants with cognitive impairment (three with MCI and two with mild dementia) after which this phase ended as no changes were required to the wording of the questionnaire and it was found to be acceptable by participants. Data collected from this phase was thereafter included in the overall analysis.

Data collection phase

Participant characteristics

A total of 21 people with cognitive impairment completed the rPATDcog (five from the adaptation phase plus a further 16 from the data collection phase). The mean age of participants with cognitive impairment was 77 years and 10/21 were female (Table). Eleven carer participants were recruited (matched with 11 participants with cognitive impairment) with a mean age of 69 years old. The mean total number of medications taken by participants with cognitive impairment was 6.71 ± 2.5 (standard deviation, SD). Additional participant characteristics are shown in table S, Appendix I.

Responses to rPATDcog

Only three 'don't know' responses (to two questions: 'Do you think that you are taking medicines that you don't need anymore?' and 'Overall, are you satisfied with your medicines?') were reported to the 7 questions by 21 participants with cognitive impairment (approximately 2% prevalence). The average time taken to administer the rPATDcog was 4.4 minutes (mean, SD 2.7).

Eighty-one percent (17/21) of participants with cognitive impairment agreed that they would be happy to stop one of their medications if their doctor said it was possible. Approximately one quarter (24%, 5/21) of participants with cognitive impairment reported getting stressed if changes are made to their medications and 19% (4/21) had had a bad experience when a medication was stopped in the past (Figure).

Agreement between people with cognitive impairment and carer dyads

There were 11 dyads of people with cognitive impairment and their carers. The figure shows the results of the kappa coefficient for the seven questions of the rPATDcog with their corresponding carer rPATD questions. All demonstrated almost perfect strength agreement between responses (Cohen's kappa > 0.80) [9].

Discussion

It was feasible to administer the rPATDcog to 21 participants with mild cognitive impairment or mild dementia. The rPATDcog was found to be acceptable for use in this outpatient setting when administered by a health care professional.

Our pilot data collection phase indicated that the majority of this population are open to having one or more of their medications deprescribed if their doctor said it was possible (81%). These results are similar those previously found in older adult populations in Australia [10–12].

Previous studies have found a low to moderate level of concordance between people with cognitive impairment and their carers about their values and treatment preferences [13–15]. In these studies, carers were asked what they thought their care recipient wanted. However, the rPATD is designed to capture how the carer feels about deprescribing (i.e. it is not a proxy measure). It is interesting then, that we found a good level of agreement between our dyads. It has been previously noted that the traditional doctor-patient relationship is disrupted in the setting of progressive cognitive impairment where a carer will progressively take over the role of making decisions about medications [16]. Our results suggest that a discussion with both parties around deprescribing will not often reveal conflict.

There are several limitations to this study. The first and most important is the small number of participants, where individuals were recruited from a single site, and carers were sampled from those who had accompanied their care recipient to a specialist geriatrician appointment. Additionally, while individuals with moderate dementia were eligible to participate, none were recruited during the period of this pilot study. A larger study is required before any strong conclusions can be made.

While this study represents a small sample from a single setting in Australia, the rPATDcog has international significance and implications. It is well known that many people with dementia have complex care needs. In the context of an ageing society and predicted increase in the number of people diagnosed with dementia internationally, optimising care through deprescribing of inappropriate medications has the potential to reduce harms to the individual and release funds which can be spent on other aspects of care [2].

Previous work has established that people with dementia provide accurate and consistent responses about their values and preferences and report desire to be involved in making decisions about medications [17]. This preliminary work should encourage clinicians to initiate conversations with people with dementia and, where appropriate, with their carers, to enable deprescribing of inappropriate medications.

Conclusion

It is feasible to administer the rPATDcog to people with mild cognitive impairment. This preliminary work suggests that if their doctor said it was possible most people with mild cognitive impairment or mild dementia would stop one or more of their medication(s). While there is further work required with the rPATDcog, it has potential to be a useful tool to be used in conjunction with the carers rPATD to enhance conversations about deprescribing in practice.

Impact statement:

This preliminary work suggests that people with dementia and their carers are open to having medications deprescribed. This should encourage clinicians to consider deprescribing in this population and to discuss it with their patients with mild cognitive impairment as well as carers/family members who are involved in that person's care.

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Table: Participant characteristics

	Participants with cognitive impairment (n=21)	**Carer participant (n=11)**
Age, years (mean±SD)	77.1 ± 9.1	69.1 ± 11
Female sex, N (%)	10 (48)	6 (55)
Charlson comorbidity index (mean±SD)	2.5 ± 1.6	-
Diagnosis of cognitive impairment, n (%)		-
Mild Cognitive Impairment	10 (48)	
Alzheimer's disease	9 (43)	
Mixed	2 (10)	
Medications (mean±SD)		-
Total number	6.7 ± 2.5	
Regular	6.0 ± 2.4	
PRN (as required)	0.7 ± 0.9	
Relationship of carer to care recipient, n (%)		
Spouse/partner	-	8 (73)
Mother/father		3 (27)
Place of residence, n (%)		
Home alone	5 (24)	2 (18)[†]
Home with carer present in clinic	12 (57)	8 (73)
Home with family/friend not present in clinic	1 (5)	1 (9)
Retirement village	1 (5)	0 (0)
Residential aged care facility	2 (10)	0 (0)
Highest education completed, n (%)		
High school	6 (29)	1 (9)
Trade/apprenticeship/certificate/diploma	9 (43)	2 (18)
Bachelor/postgraduate degree	6 (29)	8 (73)
Person responsible for looking after medications, n (%)	14 (67)	-
Themselves	3 (14)	
Themselves mostly with help of family/friend	3 (14)	

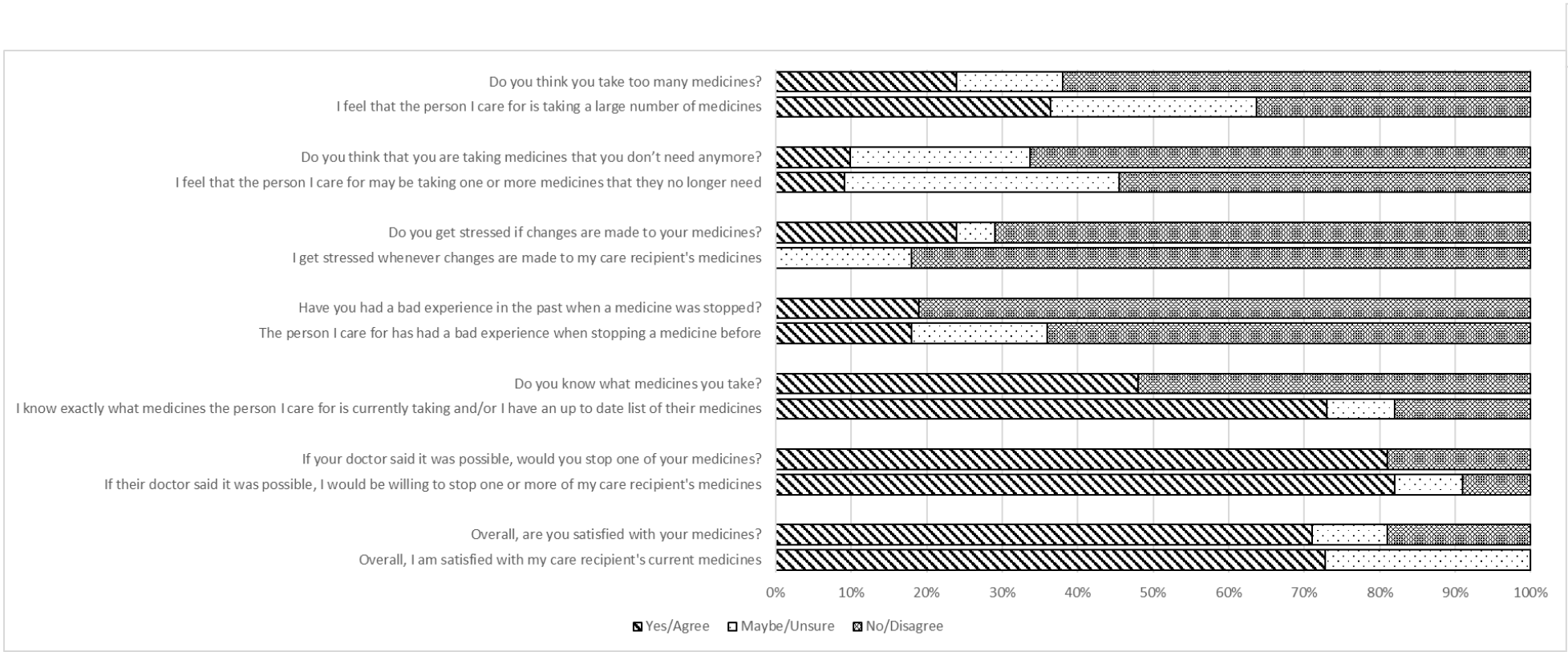
Family/friend Paid carer	1 (5)	
Reported Goals of Care‡, n (%) Extend duration of life Improve current function and quality of life Maintain current function and quality of life Be comfortable	 10 (48) 11 (52) 16 (76) 12 (57)	-
Participate in decision to take new medication, n (%)	19 (91)	-
†Carers live separately to person with cognitive impairment ‡ Patient reported goals of care may include more than one of the following Percentages may not add up to 100 due to rounding		

Legends

Figure: Responses to the rPATDcog and rPATD carers version

Responses to carer questions grouped into three categories: Agree (Strongly agree/Agree), Unsure and Disagree (Strongly disagree/Disagree)

*Agreement between the responses of the people with cognitive impairment with those of their carers to the rPTAD-cog questionnaire (n=11)


Do you think you take too many medicines?
I feel that the person I care for is taking a large number of medicines
Do you think that you are taking medicines that you don't need anymore?
I feel that the person I care for may be taking one or more medicines that they no longer need
Do you get stressed if changes are made to your medicines?
I get stressed whenever changes are made to my care recipient's medicines
Have you had a bad experience in the past when a medicine was stopped?
The person I care for has had a bad experience when stopping a medicine before
Do you know what medicines you take?
I know exactly what medicines the person I care for is currently taking and/or I have an up to date list of their medicines
If your doctor said it was possible, would you stop one of your medicines?
If their doctor said it was possible, I would be willing to stop one or more of my care recipient's medicines
Overall, are you satisfied with your medicines?
Overall, I am satisfied with my care recipient's current medicines
0%
10%
20%
30%
40%
50%
60%
70%
80%
90%
100%
Yes/Agree
Maybe/Unsure
No/Disagree
Kappa statistic*
0.80
0.84
0.89
0.88
1.00
0.89
0.90

Appendix I

Title: Development and pilot testing of the revised Patients' Attitudes Towards Deprescribing questionnaire for people with cognitive impairment

Box: Additional methods details

Method of consent

Written informed consent was obtained following the provision of verbal and written information about the study and confirmation of eligibility by the researcher. It was emphasised that both the person with cognitive impairment and carer (where present) could be participants in the study (individual consent forms were completed by both parties or by proxy consent for the person with dementia as appropriate). Clinic nurses identified potentially eligible participants and gained verbal consent from them to be approached by the researcher.

Method of questionnaire adaption

Three main changes were required to make the questionnaire suitable for people with dementia:

1) shorten the questionnaire overall
2) simplify the wording of the questions
3) simplify the response categories

The adaption was based on the principles outlined by The Dementia Engagement and Empowerment Project [1].

The older adults' version of the rPATD has twenty-two questions consisting of four factors (with five questions in each factor) plus two global questions. The two global questions, one question from each of the burden, appropriateness and involvement factors and two questions from the concerns about stopping factor were retained and modified for the people with cognitive impairment version. The items retained were based on those with the greatest item-to-total correlation of the overall factor score and therefore those most likely to correlate with the results of the overall factor. Two questions were retained from the concerns about stopping factor as this factor has the lowest internal consistency and therefore response to a single question may not be a good predictor of the overall factor [2]. The appropriateness of the items in this population was also considered by the research team.

Alterations were made to the wording of the question to change it from a first-person statement (to which there was a 5-point Likert scale attitudinal response) to a simpler question format. This corresponds with

the decision for the rPATDcog to be administered by a researcher/health care professional, rather than self-administered, as it was considered important to have an individual present during completion of the questionnaire to allow for clarification of the question and answers and in case any distress is caused by completing the questionnaire. Additionally, the response options were simplified from a 5-point Likert to 3 answer options (Yes/No/Maybe).

This process (deciding on questions to include, changing the wording) was conducted by members of the research team who have expertise in caring for and communicating with people with dementia (geriatricians and residential aged care staff) and development and validation of questionnaires. Changes were made until agreed upon by the team that it was ready for piloting.

During the adaption phase, the questionnaire was administered by one of the members of the research team and the understanding of the person with cognitive impairment was ascertained via targeted and open questions during and after completion of the questionnaire (cognitive interview technique) [3]. Necessary changes to the wording of the questionnaire were conducted iteratively until a final version was considered appropriate.

Table S: Additional participant characteristics

	Participants with cognitive impairment (n=21)	Carer participant (n=11)
Medication classes*, n (%)		-
Alimentary tract and metabolism	34 (24)	
Blood and blood forming organs	5 (4)	
Cardiovascular system	57 (40)	
Genitourinary system and sex hormones	2 (1)	
Systemic hormonal preparations (excluding sex hormones and insulin)	1 (1)	
Musculoskeletal system	6 (4)	
Nervous system	27 (19)	
Respiratory system	2 (1)	
Sensory	2 (1)	
Other (including complementary medicines)	5 (4)	
Use of medications to treat dementia symptoms, n (%)		-
Cholinesterase inhibitor	4 (19)	
Memantine	0 (0)	
Cholinesterase inhibitor & memantine	0 (0)	
None	17 (81)	
MMSE/RUDAS score$^{\infty}$ (mean±SD)	25.3 ± 3.2 (range 18-29)	-
Concession card holder, n (%)	15 (71)	-
Private health insurance, n (%)	18 (86)	-
Worked/qualified as a healthcare professional, n (%)	4 (19)	2 (18)
Country of birth, n (%)		
Australia	9 (43)	7 (64)
Other$^{\#}$	12 (57)	4 (36)
First Language, n (%)		
English	16 (76)	10 (91)
Other	5 (24)	1 (9)
Language spoken at home, n (%)		
English	18 (86)	11 (100)
Other	3 (14)	0 (0)
Medication administration aid, n (%)		
None	11 (52)	
Dosette packed by themselves	3 (14)	-
Dosette packed by a carer	1 (5)	
Dosette packed by pharmacist/nurse	6 (29)	
Participate in decision to take new medication, n (%)	19 (91)	-
Medication management roles of carer^{+}	-	
Organising and obtaining medications		7 (64)
Looking after pharmacy bills		7 (64)
Going to doctor appointments		10 (91)
Filling a dosette box		2 (18)
Administering the medications		4 (36)
Checking every now and again that care recipient is taking their medications correctly		7 (64)
Making decisions about medications with their doctor(s)		6 (55)
Helping care recipient make decisions about medications		6 (55)
Talking with nursing staff at residential care facility about their day to day health and wellbeing		2 (18)
Being called by the doctor after they have visited care recipient in their residential care facility		2 (18)
Other		1 (9)

*According to Anatomical Therapeutic Chemical (ATC) classification system by 1st level, anatomical main group, % out of all medications taken by participants (n=141).
∞ Mini-Mental State Exam (MMSE) or Rowland Universal Dementia Assessment Scale (RUDAS); both are scored out of 30 and have been found to be well correlated [4]. Cognitive testing score extracted from case notes, choice of test determined by practitioner they saw in the clinic.
included England, New Zealand, Greece, Netherlands, Croatia, China, Fiji, Bolivia and India
+carer role may include more than one of the following
Percentages may not add up to 100 due to rounding

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