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Why don't older adults with subjective memory complaints seek help?

Running title: Help-seeking for subjective memory complaints

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Subjective memory complaints, help-seeking, illness perceptions, coping, common-sense model

Key points:

- Help-seekers perceived their memory problems to be serious and made pathological causal attributions
- Help-seekers were more likely to have had a close relative with dementia

- Educational interventions regarding memory problems, in particular challenging causal attributions, may help to encourage help-seeking in people with SMCs and improve care in the early stages of dementia

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Abstract

Background

Subjective memory complaints are common amongst older adults, often causing significant distress and showing strong relationships to future cognitive decline. However, low rates of help-seeking for memory complaints are well documented. Little is known about the reasons behind the decision to, or not to, seek help with memory problems. The Common Sense Model of Illness Perception (CSM), proposes that the beliefs people hold about their health underlie help-seeking behaviour. The present study investigated factors underlying the decision to seek help in people with Subjective Memory Complaints (SMCs) within the framework of the CSM.

Methods

Cognition, illness perceptions, coping styles, depression and anxiety were assessed in 98 adults aged 50 and above with SMCs; 60 attending a Memory Clinic and 38 non-help-seekers.

Results

Objective cognitive performance did not differ between participants who had sought help and those who had not. Logistic regression revealed illness perceptions including social comparison and causal attributions to predict help-seeking behaviour. More general coping style did not predict help-seeking.

Furthermore, participants who had sought help were more likely to have a close relative with dementia.

Conclusions

The results suggest that beliefs about memory rather than objective cognitive impairment are associated the decision to seek help for subjective memory complaints. The findings suggest that providing education regarding memory problems, in particular challenging causal attributions, may help to encourage help-seeking in people with SMCs and improve care in the early stages of dementia.

Introduction

Subjective memory complaints (SMCs) are common amongst older adults (Jonker *et al.*, 2000; Ponds *et al.*, 1997) and can be a source of significant concern (Commissaris *et al.*, 1998; Mol *et al.*, 2007). However, only a minority of those with memory complaints seek help (Waldorff et al., 2008; Commissaris et al., 1993), with the prevalence of memory impairment identified in community surveys over twice that reported by General Practice (GP) registrations within the same population (Eefsting et al., 1996).

SMCs show little relationship with current cognitive abilities, but show a strong association with future cognitive decline indicating that people with SMCs are at increased risk of developing dementia (Reid and Maclullich, 2006) In the absence of routine screening, encouraging help-seeking for memory problems amongst older adults was highlighted as a priority in the National Dementia Strategy (2009). Potential benefits of help-seeking for people with SMCs fall into two general areas: i) access to memory re-training and other support to improve memory performance and reduce distress (Mowszowski et al., 2010; Mol et al., 2007; Jean et al., 2010), ii) to permit diagnosis of dementia at the earliest point therefore allowing provision of post-diagnostic counselling, allowing patients to make practical decisions about the future (Winblad et al., 2004),, and providing early treatment with disease modifying treatments as they become available (Petersen *et al.*, 2001).

For a person to seek help for a health problem, a symptom must first be recognised and attributed to a medical condition. The Common-Sense Model of Illness Perceptions (CSM) (Leventhal et al., 1984) has been used to explain help-seeking behaviour (Cameron et al., 1993; Hunter et al., 2003; Frostholm et al., 2005). When an individual experiences a threat such as a physical symptom they formulate a common sense representation, or model, of the problem. This model consists of beliefs or perceptions about the threat based on past experience, lay knowledge, information from friends and family, media and medical professionals. These beliefs and perceptions are thought to determine the coping strategies an individual employs to deal with the threat which in turn influence decisions such as that to seek help. Supporting evidence for the model has been reported in a range of conditions including breast cancer, myocardial infarction and fibromyalgia (Cameron, Leventhal et al. 1993; Kersh, Bradley et al. 2001; Grunfeld, Hunter et al. 2003; Hunter, Grunfeld et al. 2003; Walsh, Lynch et al. 2004).

There is some evidence that health beliefs and illness perceptions are involved in help-seeking in memory disorders in older adults, including normalisation of such problems through aging expectations and social sharing, or attributing memory problems to other conditions (Hodgson et al., 2004; Prohaska et al., 1987; Connell and Gallant, 1996; Werner, 2003b; Ortiz and Fitten, 2000; Knopman et al., 2000; Wackerbarth and Johnson, 2002). Conversely a greater knowledge of Alzheimer’s disease increases the propensity to seek help (Hodgson et al., 2004; Werner, 2003b; Werner, 2003a) as have perceptions of serious consequences and negative emotions (Barker et al., 1995; Hodgson et al., 2004; Werner and Heinik, 2004; Werner, 2003b). A recent study of intentions to seek help for a relative with memory problems offered some support for the CSM (Hamilton-West *et al.*2010).

The present study tests whether the CSM can explain help-seeking behaviour in people with SMCs. The aims were to (i) assess any differences in illness perceptions, coping styles and affect between people with SMCs who have sought help and those who have not, (ii) to determine the relative contribution of these factors to help-seeking, and (iii) to assess the role of personal experiences of another person with severe memory problems. This is a preliminary study performed on a convenience sample and is intended to inform future research.

Methods

Participants

Ninety-eight participants with SMCs were recruited: 60 help-seeking (HS+) (25 males; mean age 71.6 years, range=53-85, SD=8.3; mean MMSE score 27.6, range=24-30, SD=1.8; mean education=10.9 years, range=0-20, SD=2.9) and 38 non-help-seeking (HS-), (9 males; mean age 76.1 years, range=55-91, SD=9.0; mean MMSE score=27.2, range=24-29, SD=1.3; mean education = 10.7 years, range=9-20, SD=2.4). No significant differences were found between groups (p>.05) with the exception of age ($t_{(96)}$=-2.54, p=.013). Patients with a serious or unstable medical conditions or Mini-Mental State Examination (MMSE) (Folstein et al., 1975) score <24 were excluded. All participants reported subjective memory problems of onset within middle/old age which they considered to be more significant than the everyday memory lapses experienced by most people.

Procedure

A consecutive series of individuals with SMCs attending the Manchester Memory Clinic were invited to take part in the study (HS+). Additional participants with SMCs were recruited from community groups and sheltered housing projects. SMCs were identified by self-reported memory complaints with onset within middle/old age. None reported seeking help for their SMC (HS-) although 3 had mentioned their memory to their GP in the past. After obtaining informed consent, all assessments were performed at a single visit to the participant's home (Ethics Ref: 03/NM/623).

Measures

The Illness Perception Questionnaire for Memory Problems (IPQ-M) (Hurt *et al.*, 2010) is a version of the Illness Perception Questionnaire – Revised (IPQ-R) (Moss-Morris *et al.*, 2002) adapted for the use in individuals with SMCs. The measure comprises 11 subscales: identity (the symptoms attributed to SMCs), timeline acute/chronic (ideas of how long the SMCs will last), timeline stability/decline (beliefs about whether the SMCs will remain stable or deteriorate), personal control (blame) (extent to which an individual blames themselves for not trying to control their memory), personal control (helplessness) (extent to which an individual feels unable to control their memory), consequences (consequences of SMCs for the individual), emotional representation (an individual's emotional reaction to SMCs), illness coherence (to what extent SMCs make sense to the individual), treatment control (beliefs about the efficacy of treatment), social comparison (perceptions of whether memory is worse than peers) and cause of SMCs. All subscales are measured on a five point likert scale except identity which is a yes/no symptom checklist of common memory complaints. Items specifically related to memory complaints were added to the cause subscale (see Table 2). Standardised subscale scores were computed (the raw score divided by the number of items in the subscale), except for the identity subscale which is a cumulative score. A full description of the measure and its clinimetric properties can be found elsewhere (Hurt et al., 2010).

Coping was assessed using the Ways of Coping Questionnaire (WCQ) (Folkman et al., 1987) (subscales: escape-avoidance, social support seeking, self-control, confrontative, distancing, accepting responsibility, planful problem solving and positive reappraisal). Specific coping strategies were elicited using a standard vignette of an instance of forgetting. Scores were computed as a percentage representing each subscale as a proportion of total coping effort (Vitaliano et al., 1987).

Depression was assessed using the 15-item self-report Geriatric Depression Scale (GDS) (Yesavage et al., 1983) (mild depression ≥5, severe depression ≥10 severe depression). The Beck Anxiety Inventory (BAI) (Beck et al., 1988) was used to assess anxiety (mild anxiety ≥9 , moderate anxiety ≥18).

Results

Analysis of covariance (ANCOVA) was used for all between-group comparisons, controlling for the effect of age. The critical-p value was adjusted for each analysis using Bonferonni correction. Although not-significant, the group had different proportions of males and females. Subgroup analyses did not reveal any significant effect of gender and the results are not reported.

Group differences in Perceptions of SMCs, Coping and Affect (Table 1-3)

The help-seeking group scored significantly ($p \leq 0.005$) higher than the non-help-seeking group on three subscales: identity, social comparison and consequences (Table 1). The HS+ group were more likely to attribute their memory problems to a lack of blood to the brain than the HS- group ($p \leq 0.002$) (Table 2). The HS- group scored higher on attributions of loneliness. Attributions relating to diet and trauma approached significance being endorsed more frequently by non-help seekers. In relation to coping, the HS+ group scored significantly ($p<0.01$) higher on social support seeking and the HS- group higher on distancing (Table 3). No significant differences were found between groups in anxiety (mean BAI: HS+=3.4, SD=5.5, HS-=2.4 SD=4.0) or depression (mean GDS: HS+=3.7 SD=3.3, HS-=2.7, SD=2.9).

Predicting help-seeking behaviour

Hierarchical logistic regression analysis was used to determine the contribution of selected (based on group differences) illness perceptions and coping styles to group membership (i.e. decision to seek help): age, identity, consequences, social comparison, loneliness, lack of blood to the brain, distancing and social support. The model accurately predicted group membership for 87.2% of cases. The model R^2 varied between 0.591 and 0.803 suggesting the model explained a large proportion of variance in the data (Table 4). Exp *b* represents the odds of belonging to the help-seeking group, with a value greater than one indicating increased odds of help-seeking as the predictor increases, while a value less than one indicates decreased odds of help-seeking. The results suggest that attribution of memory problems to loneliness was predictive of membership of the HS- group, while attribution of memory problems to lack of blood to the brain and holding perceptions of memory as worse than others (social comparison), were predictive of HS+ group membership. Coping did not significantly predict help-seeking behaviour. Holding strong identity perceptions and less use of distancing as a coping strategy were borderline significant predictors of help-seeking. The analysis was re-run excluding the three participants in the HS- group who has previously mentioned their memory to their GP in order to control for GP referral threshold. Removal of these three participants was not found to affect the results (R^2 = .587-.804).

Exploration of reasons for help-seeking decision

The majority (66%) of help-seeking participants did so because they, or a family member, were concerned there was something wrong with their memory, while in the HS- group most (86%) did not believe their memory problems warranted speaking to their GP (86%). Only a few (11%) of the HS- group failed to seek help because they were unaware that it was available. There was no significant overall difference between groups in the proportion of people who had known someone with serious memory problems (HS+ 46%, HS- 35%) (χ^2=.987, df(1) *p*=.320), although where there was personal experience it was typically a parent in the HS+ group, and a friend in the HS- group.

Discussion

The CSM proposes that individuals hold beliefs about illness which determine how a person chooses to cope with the threat. Cameron et al. (1993) argued that when a person experiences a symptom of ill health they will only seek help when selected coping procedures prove ineffective and the individual experiences psychological distress. Therefore we would expect help-seekers and non-help-seekers to hold different perceptions of their SMCs which lead them to implement different coping methods and experience different levels of distress. In support of the CSM in the present study help-seekers perceived their memory problems to be more severe than non-help-seekers; reported more symptoms, perceived more serious consequences and judged their memory to be poorer than their peers despite their objective cognitive performance being no worse than the non-help-seekers. These dimensions of perception have been found to distinguish help-seekers in previous studies (Cameron, Leventhal et al. 1993; Kersh, Bradley et al. 2001; Grunfeld, Hunter et al. 2003; Hunter, Grunfeld et al. 2003; Walsh, Lynch et al. 2004) and logically arise together as an overall judgement of seriousness of the condition.

Both groups perceived SMCs to have a chronic timeline and a deteriorating course. This is unsurprising due to the commonly held expectation that cognitive function deteriorates with age and does not require belief in a pathological cause of memory problems. Overall, perceptions of treatment and personal control were low in both groups. This may reflect the generally low level of knowledge in the population of interventions available for memory problems and personal factors that may influence them. Cameron's model of help-seeking suggests that experiencing emotional distress related to the health threat was a pre-requisite for help-seeking. This was not supported in the present study although we did not measure distress in the HS+ group in the time leading up to initiating help-seeking.

The causal attributions made by each group provide some insight into help-seeking behaviour. The help-seeking group perceived their memory problems to have a biological or medical cause which may be amenable to treatment, whereas the non-help-seeking group perceived their memory problems to have been caused by social factors not requiring treatment. Such attributions may be associated with the decision making process.

The CSM states that the coping strategies a person selects to deal with their health problem are determined by the beliefs they hold about their illness, therefore we may expect individuals who hold different perceptions of their illness to employ different coping strategies. In support of the CSM the help-seeking group reported greater use of social support seeking whilst the non-help-seeking group reported more use of distancing. Those participants who use distancing as a coping technique are, by their nature, far less likely to seek help. The type of coping strategy employed by an individual is in part determined by whether the individual believes that anything can be done about the problem Lazarus (1992). If an individual believes that the problem is amenable to change, problem focused coping strategies are likely to be employed, while if an individual does not believe a situation can be changed they are more likely to use emotion focused coping strategies. Help-seeking participants may believe that medical intervention could improve or stabilize their memory problems, while the non-help-seeking participants who believe that little can be done to help their memory if it is seen as a result of age rather than a medical problem, may employ emotion focused coping strategies to reduce any distress that they experience.

Overall the findings of the present study provide some support for the CSM. The presence of SMCs alone is not sufficient to prompt help-seeking and the decision to seek help is unrelated to level of cognitive impairment. However, in the model the relationship between illness perceptions and outcomes is an indirect one mediated by coping. This aspect of the model was not supported, with coping style failing to significantly predict help-seeking behaviour in the logistic regression analysis. This suggests, for SMCs, that illness perceptions were directly related to help-seeking.

The qualitative information in the present study sheds some more light on reasons for help-seeking. In line with previous research (Hodgson et al., 2004) the help-seeking group were more likely to have had a parent with dementia. While this may have increased the personal perceived threat, there was no evidence that they held beliefs about hereditary cause. Instead, it may reflect more experience and knowledge of the symptoms and later stages of the disease. This may also be reflected in their greater beliefs about the seriousness of the consequences and attribution of pathological cause. The personal experience of non-help seekers, which tended to be through friends, may have involved less exposure and therefore knowledge of the subtle memory loss characteristic of the early stages of dementia. Previous research has shown that memory loss is generally perceived to be a consequence of normal ageing amongst older adults who did not have a relative with dementia (Werner, 2003b).

The present study offers useful but preliminary evidence. The use of a convenience sample of participants from a memory clinic and community groups poses limitations on the findings. Some beliefs in the HS+ group may have been a consequence of having sought help and feedback given by the Memory Clinic, e.g. attribution of memory problems to lack of blood to the brain and greater social support seeking amongst the help-seeking sample. An improved design would be to study a sample of patients who intended to seek help but had not yet done so although identifying such a sample might be problematic due to the, usually, short time periods between GP visit and memory clinic assessment. Furthermore, with increasing access to information on the internet, even those intending to seek medical help may already have acquired significant amounts of information about memory problems, accurate or not, to shape their beliefs.

The limitations of the cognitive assessment of participants must also be acknowledged. Although no difference in cognitive performance was identified between the two groups only a brief measure of cognition, the MMSE, was used. It is possible that cognitive profile and/or extent of cognitive change differed between groups but the MMSE was not sensitive enough to detect these differences.

The present study is one of the first to specifically investigate the role of perceptions, beliefs and experience in help-seeking by older adults with SMCs. Future research might usefully assess directly the knowledge of dementia in both help-seeking and non-help-seeking older adults to test the hypothesis that a lack of knowledge reduces help-seeking. Longitudinal investigation of the relationship between perceptions of SMCs and help-seeking behaviour would further highlight those perceptions most associated with the decision to seek help, which could then be targeted for intervention. The link between knowledge, beliefs and help-seeking has been seen in many health conditions (Jorm, 2000) and public education interventions have lead to increases in help-seeking in both depression and psychosis (Paykel et al., 1998; Johannessen, 1998), with promising results in urinary incontinence and breast cancer (Johnson et al., 1998; Burgess et al., 2009; Linsell et al., 2009). The present study, although preliminary, provides a basis for such an educational intervention in SMCs which might focus on possible causes and early signs of dementia, and provide information about available therapies such as memory re-training and cognitive restructuring.

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Table 1 IPQ-M Subscale Scores and Group Differences

Subscale	HS- (N=38) Mean (SD)	HS+ (N=60) Mean (SD)	F	P
Identity	8.74 (3.37)	11.8 (3.64)	13.218	<0.001
Timeline acute/chronic	3.89 (0.636)	3.97 (0.533)	0.618	0.434
Timeline stability/decline	3.32 (0.721)	3.39 (0.712)	0.345	0.559
Personal control: blame	2.83 (0.740)	2.61 (0.790)	1.905	0.171
Personal control: helplessness	3.56 (0.650)	3.36 (0.712)	1.735	0.191
Consequences	2.32 (0.826)	3.25 (0.935)	19.118	< 0.001
Emotional representation	2.75 (0.781)	3.06 (0.704)	2.537	0.115
Illness coherence	3.08 (1.03)	2.96 (1.05)	0.320	0.573
Treatment control	2.68 (0.535)	2.78 (0.709)	0.143	0.706
Social comparison	2.86 (0.512)	3.51 (0.581)	28.714	<0.001

HS+ = Help-seeking Sample, HS- = Non-help-seeking Sample

Table 2 Mean Scores for IPQ-M Cause Items and Group Differences

Cause item	HS- (N=38) Mean (SD)	HS+ (N=60) Mean (SD)	F	P
Stress or worry	3.34 (1.01)	2.9 (1.23)	3.624	0.060
Lack of concentration/ not listening properly	3.47 (0.89)	2.92 (1.21)	4.209	0.043
Loneliness	2.97 (1.42)	1.77 (0.87)	24.587	<0.001
Lack of blood to the brain	2.61 (0.95)	3.33 (0.95)	12.584	0.001
Diet	2.16 (0.86)	1.77 (0.67)	7.723	0.007
Accident or injury	1.61 (0.79)	1.97 (0.84)	3.713	0.057
Trauma e.g. death of a loved one	2.84 (1.31)	2.08 (1.15)	8.257	0.005
Chance or bad luck	2.13 (1.09)	2.73 (1.21)	5.262	0.024

HS+ = Help-seeking Sample, HS- = Non-help-seeking Sample

Only items significantly differing between groups or those approaching significance are shown

Table 3 Relative WCQ Subscale Scores and Group Differences

Coping strategy	HS- (N=36) Mean (SD)	HS+ (N=60) Mean (SD)	F	P
Distancing	.33 (.08)	.27 (.07)	12.053	.001
Social support seeking	.22 (.08)	.28 (.08)	12.002	.001
Accepting responsibility	.25 (.08)	.23 (.08)	1.129	.291
Escape-avoidance	.20 (.07)	.22 (.07)	.250	.619

HS+ = Help-seeking Sample, HS- = Non-help-seeking Sample

Table 4 Logistic Regression Model of Help-seeking: Beta values, Standard Error, Exp *b*, Confidence Intervals for Exp *b*

Model Chi-squared	Chi-squared change	Cox & Snell R squared	Nagelkerke R squared	
$\chi^2_{(8)} = 87.2$ $p < .001$	-	.591	.803	
	B(SE)	Exp *b*	P	CI
Constant	-9.64 (4.63)			
Age	.072 (0.06)	1.08	0.24	0.95 – 1.21
Identity	0.26 (0.15)	1.30	0.08	0.97 - 1.73
Social comparison	2.00 (0.94)	7.40	0.03	1.18 - 46.34
Consequences	1.16 (0.73)	3.20	0.11	0.77 - 13.32
Loneliness	-1.89 (0.53)	0.15	<0.001	0.053 - 0.43
Lack of blood to the brain	1.78 (0.70)	5.90	0.01	1.50 - 23.28
Social support seeking	5.24 (6.26)	118.96	0.40	0.01 - 40073835
Distancing	-12.28 (6.54)	0.00	0.06	0.000 - 1.71