Understanding the Barriers to Guideline Use for Depression & Anxiety in Patients with Parkinson's Disease and Dementia.

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Understanding the Barriers to Guideline Use for Depression & Anxiety in Patients with Parkinson's Disease and Dementia.

by

Zahra Goodarzi

A THESIS
SUBMITTED TO THE FACULTY OF GRADUATE STUDIES
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Abstract

Background: Depression or anxiety are under-diagnosed and under-treated in those with dementia or Parkinson’s disease (PD).

Objectives: The objectives of this thesis were to first understand what high quality guideline recommendations exist for depression or anxiety in dementia or PD. Secondly to explore the barriers and facilitators to implementing these guidelines.

Methods: A systematic review of guidelines was completed, following the PRISMA statement and using the AGREE II tool to assess quality. In focus groups with stakeholders, we assessed the barriers and facilitators to guideline use and implementation.

Results: Guideline quality scores were lowest for stakeholder involvement, applicability, and editorial independence. Major barriers to use included a lack of evidence, lack of applicability to the practice population, impractical or out of date recommendations.

Conclusions: There are guideline recommendations for depression or anxiety in dementia and PD. However, practitioners have difficulty with implementation due to a lack of evidence and applicability.
Acknowledgements

Acknowledgement of Graduate Support

I would first and foremost like to thank Dr. Holroyd-Leduc, she talked me into Geriatrics in the first place and I haven’t looked back since. Her unyielding support, encouragement, experience and kindness, has made my career possible. The mentorship in all aspects of life that she has provided is more than any student could ask for and I’m humbled to have received such a wonderful mentor, ally and friend.

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Although you are my colleagues I think of you all as friends.
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Dedication

For my family. My father has always encouraged science and encouraged me to ask questions and learn. He supported me as a child with rocks in my pockets because I wanted to be a geologist like him and even more when I took the journey through medicine. My loving mother is and always has been my rock. He unwavering support and love makes it possible for me to succeed and achieve my goals. While also reminding me of the reason I chose to do all this in the first place. My brother and sister are both inspirations and I would have definitely fallen flat on my face in school without them both, or at least never understood physics or semi colons. They both work tirelessly in their respective fields and remind me constantly of how lucky I am to have such a team around me. And to Mark, I don’t know what I would do with out you, your support and love means everything to me. Thank-you for keeping me sane(ish).

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<th>Full Form</th>
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<tbody>
<tr>
<td>AAN</td>
<td>American Academy of Neurology</td>
</tr>
<tr>
<td>ACID</td>
<td>Anxiety in Cognitive Impairment and Dementia</td>
</tr>
<tr>
<td>AHS</td>
<td>Alberta Health Services</td>
</tr>
<tr>
<td>APA</td>
<td>American Psychiatric Association</td>
</tr>
<tr>
<td>AQuAS</td>
<td>Agency for Health Quality and Assessment of Catalonia</td>
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<td>Avalia-T</td>
<td>Galician Health Technology Assessment Agency</td>
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<tr>
<td>BCW</td>
<td>Behaviour Change Wheel</td>
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<td>BDI</td>
<td>Beck Depression Inventory</td>
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<tr>
<td>BPA</td>
<td>British Association of Psychopharmacology</td>
</tr>
<tr>
<td>CADASIL</td>
<td>Cerebral Autosomal-Dominant Arteriopathy with Subcortical Infarcts and Leukoencephalopathy</td>
</tr>
<tr>
<td>CBT</td>
<td>Cognitive Behavioural Therapy</td>
</tr>
<tr>
<td>CCCD TD4</td>
<td>Canadian Consensus Conference on the Diagnosis and Treatment of Dementia</td>
</tr>
<tr>
<td>CHREB</td>
<td>Conjoint Health Research Ethics Board</td>
</tr>
<tr>
<td>CI</td>
<td>Confidence Interval</td>
</tr>
<tr>
<td>CIHR</td>
<td>Canadian Institute of Health Research</td>
</tr>
<tr>
<td>CNSF</td>
<td>Canadian Neurological Sciences Foundation</td>
</tr>
<tr>
<td>CPG</td>
<td>Clinical Practice Guideline</td>
</tr>
<tr>
<td>CRCD</td>
<td>Clinical Research Centre for Dementia</td>
</tr>
<tr>
<td>CSDD</td>
<td>Cornell Scale for Depression in Dementia</td>
</tr>
<tr>
<td>DMAS</td>
<td>Dementia Mood Assessment Scale</td>
</tr>
<tr>
<td>DSM</td>
<td>Diagnostic and Statistical Manual of Mental Disorders</td>
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<tr>
<td>ECT</td>
<td>Electroconvulsive Therapy</td>
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<tr>
<td>EFNS</td>
<td>European Federation of Neuroscience</td>
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<tr>
<td>FPs</td>
<td>Family Practitioner</td>
</tr>
<tr>
<td>FG</td>
<td>Focus Group</td>
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<tr>
<td>FMC</td>
<td>Foothills Medical Centre</td>
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<tr>
<td>GAD</td>
<td>Generalized Anxiety Disorder</td>
</tr>
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<td>GDS</td>
<td>Geriatric Depression Scale</td>
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<tr>
<td>GRADE</td>
<td>Grading of Recommendations Assessment, Development and Evaluation</td>
</tr>
<tr>
<td>GUIDE-IT</td>
<td>Guideline Implementability Tool</td>
</tr>
<tr>
<td>HADS</td>
<td>Hospital Anxiety and Depression Scale</td>
</tr>
<tr>
<td>HDRS</td>
<td>Hamilton Depression Rating Scale</td>
</tr>
<tr>
<td>ICD</td>
<td>International Statistical Classification of Diseases and Related Health Problems</td>
</tr>
<tr>
<td>ICSI</td>
<td>Institute for Clinical Systems Improvement</td>
</tr>
<tr>
<td>LTC</td>
<td>Long Term Care</td>
</tr>
<tr>
<td>MADRS</td>
<td>Montgomery Åsberg Depression Rating Scale</td>
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<tr>
<td>MDD</td>
<td>Major Depressive Disorder</td>
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<tr>
<td>MDS</td>
<td>Movement Disorders Society</td>
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<td>MoCA</td>
<td>Montreal Cognitive Assessment</td>
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<tr>
<td>NICE</td>
<td>National Institute of Clinical Excellence</td>
</tr>
<tr>
<td>Abbreviation</td>
<td>Definition</td>
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<tr>
<td>OR</td>
<td>Odds Ratio</td>
</tr>
<tr>
<td>P</td>
<td>Participant</td>
</tr>
<tr>
<td>PCN</td>
<td>Primary Care Network</td>
</tr>
<tr>
<td>PD</td>
<td>Parkinson's Disease</td>
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<tr>
<td>PDC –dAD</td>
<td>Provisional Diagnostic Criteria for Depression in Dementia</td>
</tr>
<tr>
<td>PLM</td>
<td>Periodic Limb Movement Syndrome</td>
</tr>
<tr>
<td>PRESS</td>
<td>Peer Review of Electronic Search Strategies</td>
</tr>
<tr>
<td>PRISMA</td>
<td>Preferred Reporting Items for Systematic Reviews and Meta-Analyses</td>
</tr>
<tr>
<td>QUAL</td>
<td>Qualitative</td>
</tr>
<tr>
<td>Quan</td>
<td>Quantitative</td>
</tr>
<tr>
<td>RAID</td>
<td>Rating Anxiety in Dementia</td>
</tr>
<tr>
<td>RBD</td>
<td>REM Sleep Behaviour Disorder</td>
</tr>
<tr>
<td>RCT</td>
<td>Randomized Control Trial</td>
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<tr>
<td>REM</td>
<td>Rapid Eye Movement</td>
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<td>RGH</td>
<td>Rockyview General Hospital</td>
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<tr>
<td>RLS</td>
<td>Restless Legs Syndrome</td>
</tr>
<tr>
<td>RR</td>
<td>Risk Ratio</td>
</tr>
<tr>
<td>SCN</td>
<td>Strategic Clinical Network</td>
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<tr>
<td>SD</td>
<td>Standard Deviation</td>
</tr>
<tr>
<td>SHC</td>
<td>South Health Campus</td>
</tr>
<tr>
<td>SIGN</td>
<td>Scottish Intercollegiate Guidelines Network</td>
</tr>
<tr>
<td>SMD</td>
<td>Standard Mean Difference</td>
</tr>
<tr>
<td>SSRI</td>
<td>Selective Serotonin Reuptake Inhibitor</td>
</tr>
<tr>
<td>TCA</td>
<td>Tricyclic Acid Antidepressants</td>
</tr>
<tr>
<td>TCMS</td>
<td>Transcranial Magnetic Stimulation</td>
</tr>
<tr>
<td>TDF</td>
<td>Theoretical Domains Framework</td>
</tr>
<tr>
<td>UPDRS</td>
<td>Unified Parkinson's Disease Rating Scale</td>
</tr>
<tr>
<td>WFBSO</td>
<td>World Federation of Societies of Behavioural Psychiatry</td>
</tr>
<tr>
<td>WHO</td>
<td>World Health Organization</td>
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</table>
CHAPTER 1: Introduction

1.1 Background

Depression affects more than 350 million people worldwide (1). Psychiatric disorders such as depression and anxiety have significant consequences for patients, caregivers, and society (2). These illnesses are associated with high economic cost, significant disability, and premature mortality due to suicide (3, 4).

Both depression and anxiety are common in patients with neurologic diseases, such as dementia or Parkinson’s disease (PD), and result in morbidity and worsened outcomes (5). Dementia is a chronic neurodegenerative disease resulting in progressive cognitive and functional impairment. The prevalence of dementia is expected to rise from 1.5% to 2.8% by 2038, reaching approximately 1.1 million cases in Canada (6). A recent study of dementia patients predicted the prevalence of depression to be 25%, although estimates range from between 10 to 62% (7-9). This is especially concerning, given the population prevalence of major depressive disorder is 6.7% in the USA and 3.9% in Canada (10, 11). Anxiety symptoms also occur in up to 75% of dementia sufferers (12).

Parkinson’s disease is a chronic neurodegenerative motor disease resulting in symptoms of rigidity, tremor, and bradykinesia (13). By the year 2030, it is projected that there will be between 8.7 and 9.3 million individuals over the age of 50 with PD worldwide (14). Non-motor symptoms, including depressive and anxiety disorders, are also common in PD (5, 13, 15). Depression and anxiety represent a common non-motor symptom in PD patients. When compared to age matched controls in the general population, the proportion with depression or anxiety is considerably higher in PD (13). On average, 35% of PD patients experience clinically relevant depressive symptoms and 17% suffer major depression (16). Anxiety disorders are also common in PD with prevalence ranging from 3.6 to 40% (17).

Despite awareness of these common comorbidities, depression and anxiety remain under-diagnosed and under-treated in those with neurologic diseases (5, 13, 18-22). Only 20% of PD patients diagnosed with depression receive therapy (23), despite the availability of effective treatments (45, 58). Patients with comorbid neurologic and depressive or anxiety disorders have poorer outcomes with reduced quality of life, higher premature mortality, increased suicide risk, poor functional status, and worsened cognition (24-29).
The use of guidelines is one method of addressing gaps in care (30). Guidelines are meant to provide a concise summary of evidence to reduce care discrepancies, improve quality of care, and reduce knowledge gaps (30, 31). This is achieved by collecting and reviewing best available evidence based on a systematic review of the literature, and appropriately combining evidence with clinical expertise and patient preferences (30). Guidelines target practitioners who can apply the recommendations to clinical decision-making (30).

1.2 Rationale

Canada spent over 42 billion dollars on mental health in 2011, and a significant portion of the provincial health care budget is devoted to this issue (32, 33). Depression is the second leading cause of global disease burden, measured by years lived with disability (34). Depression and anxiety management has been identified as a major focus for policy reform and research by the World Health Organization (WHO), Alberta Strategic Clinical Networks (SCNs), and the Mental Health Commission of Canada (1, 32, 35).

Available evidence for the effective diagnosis and treatment of depression and anxiety in patients with PD and dementia is summarized in guidelines (36, 37). Guidelines are a means of improving quality of care by disseminating and implementing best available evidence (30, 31). High quality guidelines are clear, explicit, rigorous, and well disseminated; and their use improves clinical practice (31). In the setting of PD and dementia, guidelines should promote appropriate management of depression and anxiety based on high quality evidence (38-41). Despite available guidelines, these disorders remain under-diagnosed and under-treated, suggesting these guidelines are underused (41-43).

Underuse of these guidelines represents a significant knowledge-to-practice gap, which affects our patients, their caregivers and the health-care system. Availability of multiple guidelines from different countries, associations, and organizations results in uncertainty in the medical community. This uncertainty stems from differences in quality, methodological rigour and/or context by which each of these guidelines were developed.

Using the knowledge-to-action cycle as a framework, we propose to first enable knowledge synthesis by a systematic review and appraisal of the evidence across the multiple available high quality guidelines. This evidence was then used to inform the investigation of barriers and facilitators to the use of these guidelines with focus groups of knowledge/end-users
in a qualitative study.

1.3 Literature Review

1.3.1 Defining Depression & Anxiety

Depression is a chronic illness associated with core symptoms of low mood and decreased interest or pleasure (44). This change in mood must represent a change from a persons prior functioning (44). Depressive disorders include major depressive disorder (MDD), persistent depressive disorder, and depressive disorders due to another medical condition (44). The full diagnostic criteria for MDD are outlined in Box 1. In persistent depressive disorder symptoms are noticed for more days than not for a time period of 2 years (also meeting the criteria of B-E as outlined in Box 1 under MDD) (44). These individuals experience depression in the presence of two or more of: increased or decreased appetite, insomnia or hypersomnia, fatigue or low energy, low self esteem, poor concentration, difficulty making decisions, or feelings of hopelessness (44).

| Box 1. Diagnostic and Statistical Manual of Mental Disorders (DSM) V Criteria for Major Depressive Disorder (MDD) |
| A. Five or more of the following symptoms, present in the same 2 week period and represent a change from prior function and occur most of the day most days; with at least one symptom being depressed mood or anhedonia: |
|   a. Depressed mood |
|   b. Anhedonia –decreased interest or pleasure in almost all activities. |
|   c. Change in weight of 5% either gain or loss. Increased or decreased appetite. |
|   d. Insomnia or Hypersomnia |
|   e. Psychomotor Agitation or Retardation. |
|   f. Fatigue, Loss of Energy |
|   g. Feelings of Worthlessness or Guilt |
|   h. Poor Concentration or Indecisiveness |
|   i. Recurrent Thoughts of Death or Suicidal Ideation |
| B. These symptoms cause clinically significant distress or impairment in function. |
| C. The episode is not in the setting of substance use or another medical condition. |
| D. The major depressive episode is not better explained by schizoaffective, schizophrenia, schizophreniform, delusional disorders or other psychotic disorders. |
| E. There has never been a manic or hypomanic episode. |

Anxiety disorders include, but are not limited to: generalized anxiety, panic disorders, and anxiety due to another medical condition (44). In generalized anxiety disorder (GAD), the individual experiences excessive anxiety and worry more days than not over a 6 month period
This anxiety is associated with 3 or more of the following: restlessness, fatigue, difficulty concentrating, irritability, muscle tension, or sleep disturbance (44). The symptoms of anxiety must be associated with significant impairment of function and unexplained by other psychiatric illnesses (44). Panic disorder refers to a condition where the individual has recurrent panic attacks (44). Anxiety disorder due to another medical condition is when a medical condition is the cause for anxiety or panic symptoms (44).

1.3.2 The Burden of Comorbid Depression or Anxiety

Depression and anxiety frequently co-occur with neurologic disease, which highlights the importance of investigating them together (5, 13, 15, 45). It has been demonstrated that symptoms of depression in PD or dementia contribute to reduced quality of life, poor therapy adherence, worsened cognition, increased mortality, and increased functional limitations (46, 47). In PD, anxiety has been associated with gait dysfunction or freezing, poor functional status and quality of life, and increased motor symptoms (17). Caregiver burden is also higher if patients with PD or dementia experience anxiety or depression (48).

Overlap in symptomatology, difficulties with functional status, communication, use of caregiver reports, and stigma of mental illness all contribute to under-diagnosis of depression or anxiety in the context of PD and dementia (5, 8, 9, 21, 48-53). The diagnosis of anxiety and depression is typically confirmed by an interview with a mental health team (54). Since mental health resources are often scarce, detection can be facilitated through the use of tools for case-finding (19, 55). Case finding ensures that a sensitive tool is used to identify those with possible depression or anxiety requiring further assessment (13, 54). Overall, the diagnosis of depression or anxiety in PD or dementia is possible in a timely and accurate fashion.

The hazard ratio for depression in PD is 4.06 (95% Confidence Interval (CI) 3.15,5.23) compared to those without PD, and this ratio increases to 4.26 (95% CI 3.29,5.51) when adjusted for confounders (56). A systematic review of depression in PD patients found that 35% experience clinically relevant depressive symptoms, and 17% suffer from major depression (16). Persons with PD also experience anxiety disorders, with estimates ranging between 3.6 to 40% (17). However, a 2013 study estimates the prevalence of anxiety at 55% and depression at 56% (57). Anxiety and depression overlap in nearly half of PD patients (57). PD patients with anxiety were typically younger and female; and those with depression had severe PD, lower cognitive
performance, and increased comorbidities (57). Many studies have found an association between prevalence of depression or anxiety and age at diagnosis, duration of disease, PD severity, autonomic symptoms, and the frequency and fluctuation of motor symptoms (5, 13, 15). A systematic review of the prevalence of anxiety disorders in PD identified the average point prevalence of anxiety disorders to be 31%, with 14% of patients experiencing generalized anxiety disorder (58).

Anxiety in PD is associated with increased gait abnormalities and complications of therapy (17). Depression in PD has been linked to exaggerated motor symptoms and higher disease severity (17). A recent longitudinal study found that those with depression were often less educated, female, on less dopamine agonists, and had greater fluctuations in motor symptoms (59). In addition, those with depression had more disability than those not currently suffering depression (59). These represent key findings, that comorbid depression or anxiety is associated with worsened outcomes for these patients, and thus represents a target for improving care (15, 57).

The estimated prevalence of depression in dementia has historically been quoted as 25%, although there is a reported range between 10 to 62% (7-9). A longitudinal study looking at 27,776 patients in a national registry from 2005 to 2013 compared depression in dementia to those with normal cognition and found the odds ratio (OR) to be 2.64 (95% CI 2.43-2.86) (60). This demonstrates that those with dementia had much higher odds of depression than those without (60). Anxiety symptoms occur in up to 75% of those with dementia (12, 48). Both depression and anxiety reduce quality of life for persons with dementia (8, 9, 20, 48, 61-63). These comorbid disorders worsen cognition, increase institutionalization, increase caregiver burden, and decrease functional abilities (8, 9, 20, 48, 61-63).

When discussing anxiety or depression, there is a concern that potential stigma associated with psychiatric diseases could play a role in under-diagnosis and under-treatment. This has been demonstrated repeatedly in the general psychiatric literature across the continuum (35, 64). Community level interventions aim to reduce stigma and therefore improve care for those with mental illness (35). The potential impact of stigma is magnified when considering comorbid depression or anxiety in neurologic diseases, given the additional stigma that associated with neurologic disease (12).
There are few studies examining the stigma of mental illnesses in dementia and PD (12, 65). One qualitative study investigated attitudes of those with PD towards causes and treatment of depression (65). It was estimated that approximately half of the participants in the study had concerns about stigma, and in some cases this was a deterrent to therapy (65). One large, multicentre, longitudinal study found that those who perceived stigma of dementia diagnosis led to increased anxiety (12).

1.3.3 Diagnosis and Available Therapy

Diagnosis of depression or anxiety in PD and dementia can be facilitated using case finding tools to screen these high-risk groups (9, 48, 54, 55). Case finding tools can be applied in varied settings to detect those likely to have either depression or anxiety. It is important to note that a positive result on screening tools should be followed by a clinical interview with a psychiatrist or trained professional to confirm diagnosis and plan further management. These tools enable practitioners to accurately identify patients who need further assessment by mental health services.

There are several validated tools for the detection of depression in PD and dementia. The largest study covering detection examined nine tools for depression in PD (54). They found the Geriatric Depression Scale 30 (GDS) to be ideal given its psychometric properties, ease of use, and non-copyright status (54). Of 24 tools identified by systematic review, 4 had sufficient data for meta-analysis (GDS, Montgomery Åsberg Depression Rating Scale (MADRS), Beck Depression Inventory I/IA (BDI), and the Unified Parkinson’s Disease Rating Scale (UPDRS)) (66). The GDS-15 had the highest sensitivity 0.81 (95%CI 0.64, 0.91) and specificity of 0.91 (95%CI 0.87, 0.94) when pooled across best reported cut offs (66). However, this estimate had high heterogeneity due to the comparison across different thresholds. This heterogeneity was eliminated when compared across the same cut offs, with the highest sensitivity at a cut off of 5, 0.91 (95%CI 0.83, 1.00) (66).

The Parkinson Anxiety Scale is a patient and proxy rated tool based on an extensive review of other tools and through a Delphi procedure (67). This tool demonstrated a greater area under the curve than other anxiety tools (67). Additionally, the Beck Anxiety Inventory, Hamilton Anxiety Rating Scale and the Geriatric Anxiety Scale have demonstrated validity (68).

There are also several valid tools for detecting depression in dementia. Commonly used
tools include the Cornell Scale for Depression in Dementia (CSDD), Hamilton Depression Rating Scale (HDRS), and GDS-30 (69). When compared in a meta-analysis the CSDD and HDRS were found to have the highest sensitivities of 0.84 (95% CI 0.73, 0.91) and 0.86 (95% CI 0.63, 0.96) respectively (69). The GDS had a much lower sensitivity at 0.62 (95% CI 0.45, 0.76) (69). All estimates had heterogeneity, likely due to comparison across different cut offs (69). The much lower accuracy of the GDS is likely because the tool’s self rating, and depends on the recall of the persons with cognitive impairment (69). The CSDD and HDRS incorporate an interview with the caregivers, which likely increases accuracy, but also increases time and resources for administration (69).

There are few anxiety tools tested in dementia. The Anxiety in Cognitive Impairment and Dementia tool (ACID) (70) and the Rating Anxiety in Dementia tool (RAID) (71) were designed specifically for dementia. The RAID tool is a structured interview with patient and caregiver, and demonstrated an AUC of 0.8 (95% CI 0.64-0.96) (71). With a sensitivity of 0.9 and specificity of 0.67 at a cut off of 10 (71), this tool appears to be accurate. The psychometric properties of the ACID were examined in long term care (LTC) patients (70). ACID consists of two parts, one with the patient and a second with the caregiver (70). This was to address the concern that many tools used in cognitive impairment focus solely on caregiver reports (70). Good internal consistency and convergence between the two parts has been found in this tool (70).

There are non-pharmacologic and pharmacologic therapies available for depression and anxiety in PD and dementia; however, there is heterogeneity in the evidence for some therapies (47, 72). This area of research, especially the treatment of anxiety, has not been adequately explored (72). Many studies are either too small or non-controlled (72).

### 1.3.3.1. Non-pharmacologic therapy

There are available therapies for anxiety or depression in PD and dementia (5). For PD, a variety of therapies for depression have been demonstrated to be effective, starting with cognitive behavioural therapy (CBT) (5). A randomized control trial (RCT) in 2011 demonstrated that CBT resulted in lower depression scores, anxiety, better quality of life and coping skills than the monitored group (73). Group CBT had a larger treatment effect than pharmacologic interventions with an effect size of 1.57 versus 0.69 for all antidepressants (72).
A 2015 systematic review identified 12 RCTs examining CBT compared to psychotherapy for depression in PD (74). When pooling 10 studies with the Hamilton Depression Rating Scale as an outcome, a significant improvement was found with brief psychotherapy over controls (Standard Mean Difference (SMD) -1.45 (95% -2.00 to -0.91; p<0.00001), with high heterogeneity (I²=91%, P<0.00001) (74). Two studies also found improvement in cognition quantified with the Montreal Cognitive Assessment (MoCA) when treating depression (74). Their subgroup analysis found that brief psychotherapy had more improvement on the depression scale than CBT (74). There also appeared to be cultural differences, with the effect of brief psychotherapy in China being better than the USA (74).

There is also evidence for the use of electroconvulsive therapy (ECT) in PD with depression (75). There are 4 studies that examine exercise interventions in PD, and measure depression on a rating scale (76). However, none of the exercise studies identified improvement in mood symptoms (76). Interestingly transcranial magnetic stimulation, has also been found to have a positive effect size for depression (72).

In dementia, a systematic review of psychosocial interventions found that psychosocial interventions such as CBT, interpersonal therapy, and counselling had a positive effect across 6 RCTs (total N = 439) (77). When added to usual care, psychological interventions were effective in reducing depression/anxiety and low risk (77). Generally, these therapies are often limited to patients with mild dementia, although some have been adapted for severe dementia patients and caregivers (8, 9). Five out of the six RCTs had a high risk of bias (77). There are many individual trials examining other non-pharmacologic interventions. Both pet therapy (78) and group music therapy (79) have demonstrated improvement of depressive symptoms as measured by mood/depression scales. Evidence for exercise is heterogeneous, with only one of four trials finding improvement in depression as an outcome (80).

1.3.3.2. Pharmacologic Therapy

Pharmacologic therapy is often considered in both of these groups of patients, to augment effects of non-pharmacologic interventions. In a 2013 systematic review, nine placebo controlled RCTs addressing treatment for depression or anxiety in PD were reviewed (72). A moderate to large pooled effect size was identified, which demonstrated some reduction in symptoms with antidepressants (citalopram, desipramine, nortriptyline, paroxetine and venlafaxine) for
depression (moderate; SMD = 0.71; 95% CI -1.33, 3.08) and anxiety (large; SMD = 1.13; 95% CI -0.67, 2.94) compared to placebo (72). Interestingly, a large and significant effect for Omega-3 supplements was identified (SMD=0.92; 95% CI 0.15, 1.69) (72). The conclusion from this systematic review was that more studies with larger sample sizes and greater methodological rigor are needed to improve understanding of the effect of pharmacologic therapy (47, 72).

A systematic review of antidepressant therapy in PD patients found an overall risk ratio (RR) for response to antidepressants compared to placebo of 1.36 (95% CI 0.98, 1.87). However their sensitivity analysis found a RR of 1.41 (95% CI 1.01, 1.96) when a study of low quality was removed and 1.48 (95% CI 1.05, 2.10) when a study at risk of bias was removed (47). This emphasizes the need for larger, higher quality studies.

Alternative therapies were examined in a review of traditional Chinese medicine (81). When combined with usual pharmacologic therapy, traditional medicine improved scores on the HDRS (Weighted Mean Difference -4.19 (95% CI -5.14, -3.14) versus just pharmacologic therapy alone across 10 studies (81). However, they caution their results given the low quality of the included studies (81).

The most recent systematic review of pharmacologic therapy for depression in dementia patients found that there were two studies demonstrating benefit with antidepressants, and five that did not. There was significant heterogeneity between these studies, and many were underpowered (61). From the six trials there was a pooled OR of 2.12 (95% CI 0.95-4.70, p=0.07) for response rates with an antidepressant versus placebo in those with depression and dementia (response rate was defined as either improvement on a global assessment or >= 50% improvement on the HDRS or MADRS) (61). The authors concluded that although there was a trend towards a positive effect for antidepressants, statistical analysis was non-significant (61). However, variable methodology and underpowered studies confounded the results (61). The largest clinical trial included 326 patients on two antidepressants (sertraline and mirtazapine) and found no statistically significant difference between treatment and placebo groups (82). However, there were concerns with loss to follow-up, recruitment, and perhaps measurement bias (82). One key finding was that there were fewer reported neuropsychiatric symptoms, decreased depression scores (not significant), and improved quality of life on one drug (mirtazapine) (82). These results are similar to the conclusions of a 2002 Cochrane Review (83). Further research on the pharmacologic management of depression in dementia is warranted,
perhaps examining other agents (e.g. venlafaxine or cholinesterase inhibitors) and impact of caregiver interventions (84).

Similar results are seen in anxiety therapy for dementia patients, where antidepressants have been used if non-pharmacologic therapy failed (12). There has been a recent pilot study examining CBT for anxiety in dementia, demonstrating early feasibility, cost neutrality, and effectiveness in a brief intervention (85).

There are diagnostic tools and therapies available for these patients. Nevertheless, depression and anxiety are often under recognized and under treated due to stigma, functional limitations, symptomatic overlap, and lack of knowledge, among other potential barriers (9, 13, 20). This represents a knowledge-to-practice gap, and an opportunity to improve care for these patients. High quality guidelines to address comorbid depression or anxiety could improve appropriateness of care, by streamlining the use of mental health resources based on the evidence. Evidence informed practice should increase efficiency of allocation and use of scarce mental health resources to address specific care needs.

1.3.4. Availability of Guidelines to Bridge the Gap

Clinical practice guidelines (CPGs) are “systematically developed statements to assist practitioner and patient decisions about appropriate healthcare for specific clinical circumstances” (86). In a constantly evolving landscape of evidence, CPGs aim to synthesize the best evidence and expert opinion to aid health care providers in decision-making, and reduce variation in care (87-89). CPGs have a role in enabling and supporting decision making to improve patient care (87, 88). There is a growing body of evidence examining the effect of guidelines on patient care and the barriers to the implementation of CPGs (87, 90). Despite the availability of CPGs, they remain underused. Much recent study and emphasis has been placed on guideline implementation and understanding underutilization of CPGs (87).

To support high quality care for these patients, experts in their field have created guidelines informed by the best available evidence (45). Guidelines are available across different countries and languages to improve accessibility (45). In some cases guidelines are published with permission in multiple journals (45). However, there is still an evidence to practice gap (91).
So why is guideline uptake and implementation poor? Lack of time is a big concern of the modern practitioner, with many feeling there isn’t enough time to learn and effectively implement guidelines (91). Negative perceptions or lack of awareness/knowledge also play a role (91). In a landmark study in 1999, Cabana et al. found 293 potential barriers to guideline adherence (45). Major barriers were the lack of ‘awareness, familiarity, agreement, self efficacy, outcome expectancy, ability to overcome the inertia of previous practice and external barriers to perform recommendations’ (45). The review highlighted that barriers vary according to setting, and major identified barriers should be considered during the guideline development stage (45).

1.3.5. Guideline Implementation

Three recent methodological papers outline the different aspects of developing quality CPGs (92-94). Many aspects of CPG development are examined, including involvement of the target audiences, clear selection of topics, guideline group composition, conflicts of interest, types of evidence, values and economic synthesis, grading, presentation, updating, implementability, and how to address comorbid conditions (92-94). Usual pitfalls and strategies to overcome them are identified for each of the above aspects (92-94). In a sense by providing guidelines for CPGs, the aim is to align and improve the overall quality of guidelines and hopefully their implementation.

A guideline implementability framework was developed to identify what components of guidelines facilitate use (87). They identify that two major components of implementability are guideline format and content. They identified 22 elements that were organized in to the domains of usability, adaptability, validity, applicability, communicability, accommodation, implementation and evaluation (87). Each element is described with examples, allowing guideline development groups to incorporate these features (87). Once a guideline is created, the dissemination needs to be tailored to the audience using education, incentives, feedback, clinical support systems, and engagement of stakeholders (87). Guideline implementation must be iterative; guidelines must be evaluated and used to inform further quality improvement and evidence generation (87).

The goal of the guideline will determine how information is conveyed (95). If the focus is on clinicians, then the guideline must be easy to use, clear, display valid evidence, have information on required training, and discuss how to apply recommendations (95). The level of
detail should vary based on whether the physician is a generalist or specialist. All of this differs from the information policy makers may want on resource use or implications to the larger healthcare system (95).

A realist review determined that 6 domains influenced the implementation of a guideline (96). These were covered in 2 main goals: creation of content (stakeholder involvement, evidence synthesis and considered judgement) and communication of content (implementation feasibility, message and format) (96).

A scoping review of 10 years of implementation research identified that the most commonly used tools were education of stakeholders, printed materials, and reminders (97). They highlight that although there were 51 strategies identified for implementation, their effectiveness appeared to be variable (97). There are several identified areas of improvement for CPGs, which include tailoring guideline recommendations, assessing barriers to use, selecting/tailoring implementation interventions, and monitoring use/outcomes (87, 98).

As with any evidence, guidelines need clear implementation plans to be created in order to improve their use (93). What is typically unclear is where the responsibility of implementation falls. (93). Given this, several tools have been developed to help aid the guideline committee choose and incorporate implementation tools as part of guideline development (99-102). This assessment starts with an evaluation of the domains of an implementability framework (87). A series of interviews have been completed with guideline organizations and identified that implementation methods typically varied due to resources (103). However, a common option was to include implementation plans as part of the guideline (103).

Two tools have been created to aid in implementation including the Guideline Implementability Tool (GUIDE-IT) (102) and a checklist for planning implementation (101). GUIDE-IT involves 3 steps, engaging end-users (usually FPs), a process to evaluate the implementability of a guideline, and then the provision of the end-user evaluation to the guideline developer (102). Further evaluation with an RCT is taking place to see if the use of this type of tool improves use of guidelines (102). The checklist differs from GUIDE-IT in that it is designed to be used as part of planning implementation in guideline development (101). The checklist includes the steps of implementation planning, implementation tools, dissemination and implementation strategies/options (101). Again this tool also warrants field testing to determine its effect on guideline use (101).
Assessment of guideline implementation is an iterative process in which we identify the evidence from guidelines and assess their use, develop tools to improve uptake tailored to a local setting, and then evaluate them (87, 98, 104). This understanding informs the objective of our study. As the area of implementation science grows, there have been many studies examining barriers and facilitators to guideline use across different specialties (43, 105-107). This establishes effectiveness, utility, and replicability of this type of study across disciplines. In this thesis, we examine the issues relevant to guideline adherence and implementation in the context of depression and anxiety in dementia or PD.

1.3.6. Guideline Adherence and Implementation in Depression or Anxiety

When measuring adherence to depression guidelines, a chart audit study in 2003 found varied practices (108). For example, 100% of practitioners documented follow-up plans but only 13.5% of patients were contacted for follow-up within 2 weeks (108). Similarly, an observational analysis by Hepner et al. looked at 20 measures of guideline adherence and found that detection of depression was associated with high adherence; but, management of suicide risk, substance use, elderly patients, and treatment refractory patients was lacking (109). From these quantitative results, it is evident that the issue of guideline adherence is prevalent and complex. Based on these results alone, reasons for the knowledge-to-practice gap are not readily apparent.

Studies examining the views of general practitioners (FPs) have identified several perceptions about general depression guidelines (110, 111). Smith et al. found that barriers revolved around perceived lack of time or resources, disagreement, access to specialists, appropriateness, and number of guideline recommendations (110). A study of psychiatrists had similar findings, with barriers including a lack of awareness/familiarity, difficult access, lack of support, and concerns about the usefulness/necessity of guidelines (112).

Forsner et al., completed a detailed focus group (FG) study of barriers and facilitators to CPGs using a controlled before and after study with guideline implementation as the intervention (113). The control clinic had a perceived lack of trust in CPGs, non-supportive environment, suspicion of financial motives or credibility of CPGs, lack of time, and a concern that CPGs would result in a loss of autonomy in practice (113). The intervention group felt that the team facilitator/leader, departmental support, communication, regular audits, multidisciplinary involvement and FGs were facilitators of CPG use (113). Common barriers were related to lack
of knowledge, skills, motivation, ability to change practice, format lacking user-friendliness, and applicability (113). Barriers were most prominent in the control clinic with overall negative concerns about their use (113). In the intervention clinic, organizational structure and support were perceived to be key to success (113).

The available literature focuses on depression guidelines, with few studies examining anxiety. Overall, evidence suggests that guideline implementation and adherence need to be addressed. To do this, the first step is to understand the barriers and facilitators to CPG use from the perspectives of the knowledge/end-users.

1.3.7. Guideline Adherence and Implementation in PD.

Two 2009 studies examined physician attitudes and awareness towards the German Society of Neurology PD diagnostic and treatment guidelines (114, 115). They found that 53.1% of practitioners were aware of the guidelines and although 59.8% of practitioners rated the content favourably, 53.3% had trouble incorporating them into daily practice (114). 82.2% of practitioners felt guidelines were aimed at improving care quality and 59.4% thought they were good for education (115). Lack of time, trouble aligning guidelines with patient preferences, lack of relevance, and lack of awareness were the major barriers as reported by 30-40% of participants (115). This stresses the need for appropriate implementation to ensure uptake (114).

Guideline adherence examined in PD found that there was moderate adherence to the German Society of Neurology PD treatment guidelines (116). Older guidelines, concerns about side effects, patient and financial considerations were cited as potential reasons for non-adherence (116). Here and in other studies, it has been demonstrated that specialists have greater exposure and awareness of guidelines than general practitioners (115-118).

There were two identified studies on the implementation of the National Institute of Clinical Excellence (NICE) PD guidelines (119). The first used a collaborative approach, engaging the stakeholders in a service area (119). They found that through assessment of the local context, understanding discrepancies between practice and guidelines, assessment of priorities, and adaptation of the guidelines, the authors were able to develop an action plan (119). The authors employed a local assessment tool, patient engagement, and education sessions (119). The assessment tool identified areas where there were gaps in care, they then developed aims to address those which were effective in improving care (119).
Another approach was implemented in a PD clinic, in which standardisation and documentation were used (120). A checklist of the main audit criteria recommended by the guideline was created and placed in the chart for each review date (120). Compliance to the recommendations improved to 100% over the process of 3 audit cycles (120). The last audit identified that the checklist was no longer used, but all criteria were met in the regular charting (120).

All of these studies emphasize the presence of barriers to guideline uptake for depression in PD, and stress the need for adequate knowledge translation and implementation of guidelines into care.

1.3.8. Guideline Adherence and Implementation in Dementia

Studies examining dementia guideline implementation have identified several concerns. A systematic review of dementia guidelines identified that across 9 guidelines there were differences in the methodologies used, and the recommendations made (121). These differences led to variation in diagnostic procedures and associated cost (between $190-$2001) (121). Another review synthesized available practice recommendations from high quality guidelines (122). Only 12 out of 39 identified guidelines were found to be of high enough quality on the AGREE II Tool to meet inclusion (122). A major issue here, was that direct comparison of guideline recommendations was not possible due to the varied evidence grading schemes used (122).

A survey of family doctors identified four major barriers to the use of dementia guidelines: lack of awareness, lack of clarity around guideline purpose, concerns about the role of industry in development of guidelines, and suggestions for guideline improvement (123). A study of guideline adherence in dementia found that approximately two thirds screen for depression, elder abuse, discussing care needs or capacity; and 50% of guidelines attend to care giver support (118). This suggests the need for better implementation of recommendations (118). When examining dementia guideline use in family practice, it was found that the diagnostic process for dementia was typically recorded and in line with recommendations, but management was poorly documented (41). Additionally, there were gaps in areas such as depression case finding with 68% of either primary or secondary care missing it (41).

Another issue identified is the issue of dementia guidelines and how they address
comorbidity (124). A review of 22 guidelines found only 60% addressed issues with one comorbidity, and 32% on multiple comorbidities (124).

Using the theoretical domains framework (TDF –explained below), Murphy et al. examined a dementia guideline implementation with family practitioners (FPs) (90). Their aim was to study the reported practices of FPs with respect to the diagnosis and treatment of dementia; and using the TDF provide explanations for the behaviours and practices that did not align with guidelines (90). After interviewing 30 FPs over 43 barriers and 35 enablers to the use of these guidelines in day-to-day care were identified (90). The TDF provided explanations for these behaviours, identifying key targets for intervention (90). Practitioners were adherent with the recommendation to complete a formal cognitive assessment, but not the recommendation to perform a formal screen for depression (90). When examining the recommended behaviour “Assess comorbid depression using a validated tool” three reported practices were identified: FPs assesses mood with a validated tool, FPs assesses mood using general indicators, and FPs does not assess mood (90). In some cases, FPs were not aware of the need to assess mood, forgot to assess mood, or felt that they could detect depression without formal assessment (90). This identifies clear areas to target for improving the use of the guideline recommendation, especially through education and reminders (90). By employing the TDF Murphy et al. was able to provide explanations for behaviours associated with guideline use. Understanding these behaviours provides actionable targets for implementation work (90).

1.3.9. Theoretical Frameworks of Behaviour Change.

Theoretical frameworks to explore behaviour are grounded in the notion that the implementation of evidence is contingent upon understanding behaviour change (125). These theories create a foundation on which one can develop an understanding of behaviours and how interventions can be targeted to them (125). The work by Michie et al. in 2009 focused on synthesizing psychological theory into the TDF, that would be relevant for use in the implementation of evidence based practice (126). Using a consensus approach, all the applicable psychological theories (128 constructs in 33 theories) were identified. These theories were then simplified and initially validated into 12 theoretical domains (Figure 1) (126). This created a framework rooted in psychological theory to understand behaviour change in the specific context of evidence based practice (74). These domains do not identify the cause or explain behaviours,
but represent a guide to relevant explanations of current behaviours and key prompts to behaviour change (126). Cane *et al.* examined the validity of the TDF and was able to refine the TDF to 14 domains (127).

The behaviour change wheel (BCW) builds on the refined TDF (125, 126). The BCW asserts that to improve evidence based practice, we need to understand the behaviour and then target interventions for change towards these behaviours (125). In order to develop tools for implementation, the intervention chosen must also be evidence based (125).

The BCW is a framework designed to understand behaviour with the goal of improving implementation (125). This is based on the idea that behaviour change interventions are crucial to integrating evidence into practice (125). The BCW was developed through completion of a systematic review of behaviour intervention frameworks (125). Nineteen frameworks were identified and evaluated for usefulness (121). This resulted in a list of interventions, which were constructed into a framework and tested for reliability (125). The BCW is comprised of three behaviour categories called the COM-B system: capability, opportunity, and motivation (Figure 1)(125). Each individual behaviour correlates with nine intervention functions for behaviour change, which can also be related to seven policy categories (125). Behaviour change interventions are activities designed to address the specific behaviour. This allows for the identification of the behaviour and direct mapping to a behaviour change intervention for a specific policy category, in order to target intervention strategies towards addressing identified barriers (125). One major advantage of the BCW is that it correlates with the TDF (Figure 1) (125, 127). This theory provides a unique and functional framework to study the implementation of evidence-based practice.

Qualitative study using this framework allows a rich understanding of issues with guideline adherence in this area. Thus, it builds on current literature and provides an in depth understanding that could not be gained from quantitative or survey type studies. The use of behaviour change theory is key and provides a framework to understand the behaviours associated with this evidence-to-practice gap. This framework also links behaviours to potential interventions to address them.
1.4. Study Objectives

The overarching aim of this thesis is to identify opportunities and strategies for optimizing guideline implementation, with the goal of improving outcomes and quality care for persons with PD or dementia and comorbid depression or anxiety.

Objective 1—Knowledge Inquiry and Synthesis.

Systematic Review: What evidence-based guidelines or consensus statements are available for diagnosis, management, and treatment of depression and anxiety in those with a dementia or PD? Which of these represent high quality evidence? To our knowledge there has been no previous systematic review of the multiple guidelines for depression and anxiety in dementia and PD.

Objective 2—Assessing Determinants of Knowledge Use.

Qualitative Study: What are the knowledge/end user’s perceived barriers and facilitators to the implementation of these high quality guideline recommendations?
1.5. Research Design
The mixed methods multiphase design for this study was comprised of two distinct phases; a quantitative followed by a qualitative aim (quan → QUAL) (128). In this study the systematic review of guidelines (quan) preceded the focus group study (QUAL). Relative priority in this multiphase study is assigned to qualitative aspect. This aspect is focused on the behaviours associated with the use of guidelines, and allows us to inform future implementation strategies.

In this case, the quantitative guideline appraisal produces a detailed understanding of the available evidence to provide context and inform a qualitative assessment of barriers to implementing the evidence. An advantage of conducting the systematic review is the synthesis of the recommendations from guidelines; versus a description of the body of literature associated with a scoping review. The systematic review however does not entirely explain the evidence-to-practice gap. The qualitative analysis of focus groups generated context for the systematic review evidence, using the TDF and BCW as an integrated theoretical framework. The qualitative focus group design was chosen over a survey design to obtain a comprehensive and detailed analysis to generate hypotheses and inform implementation interventions. The rationale for the focus groups was to allow participants to share complementary and conflicting perspectives, encouraging conversation that would not be delineated in interviews.

The mixing of data occurred in the data analysis and interpretation phases (128). Evidence from each aim built upon previously gathered data to yield a more complete understanding of the knowledge to action gap.

1.6. Methods
A systematic review of guidelines for depression or anxiety in PD and dementia was completed. This is reported based on the PRISMA Statement (129) and registered with PROSPERO (Centre for Reviews Dissemination (CRD): 42016014584) (130).

1.6.1.1. Search Strategy
The literature search was developed further with an experienced librarian (DL). Once developed the search was then reviewed by a second librarian (HLR) using the Peer Review of
Electronic Search Strategies (PRESS) checklist to evaluate the accuracy and comprehensiveness of the search strategy (131). Included databases were MEDLINE, EMBASE, and PsycINFO. Clusters of terms were used to search each database (Appendix A). The search clusters included controlled vocabulary and key words. The search organized in these clusters, first using the terms in each cluster (combined with the Boolean operator ‘OR’) and keyword searches of abstracts and titles. Then clusters were combined with ‘AND’. This was augmented by a search of the grey literature (Table 6). There were no language limitations on this search. The search date range was from 2009 to July 24, 2015. This was purposeful to include CPGs developed from the past 5 years; given the evidence that after 3 years CPGs may become out of date (132). We searched for several types of dementia including Alzheimer’s disease, vascular, frontotemporal, Lewy Body disease, Huntington’s disease, CADASIL, primary progressive aphasia, and Creutzfeldt Jakob (Appendix A). We included relevant derivatives of terms or broad key words related to depressive or anxiety disorders (Appendix A).

All citations were reviewed for eligibility by two independent researchers (BM & ZG); citations meeting initial inclusion criteria were included in full text review. If there was disagreement the full text article was pulled for review. Reference lists for all included articles were searched. If multiple guidelines were identified from a single agency, the most recent was used.

1.6.1.2. Eligibility

At the first stage of abstract review, any article that represented a guideline for PD or dementia was included. Eligibility at the full text stage required guidelines that include any recommendations surrounding depression and/or anxiety in patients with PD or Dementia. A kappa statistic was calculated to quantify inter-rater reliability.

For non-English articles, the language was determined using online translation software. Citations were translated using the online Google translate function to determine if an article was a guideline. When included, the documents were searched using translated relevant terms; for example, if a guideline pertained to PD in the abstract, the text was searched for depression or anxiety (and all translated synonyms). If those criteria were met, the full guideline was translated and reviewed.
1.6.1.3. Assessment of Quality

We used the Appraisal of Guidelines Research & Evaluation (AGREE II) tool as a framework for assessment of guideline quality (Appendix B) (133). The AGREE II tool evaluates guideline quality, but was also designed to help direct guideline development and reporting (133). There are 6 domains including scope and purpose, stakeholder involvement, rigour of development, clarity of presentation, applicability and editorial independence (133). Each domain has several questions making up a total of 23 (133). Each item is rated for quality from 7 (exceptional reporting of all criteria outlined in the AGREE II Manual) to 1 (not included or very poorly reported) (133). The higher score indicates a higher quality across rated items. It has been demonstrated that the quality across the AGREE II domains predicts guideline implementation (133). Each domain was scored independently by four reviewers, along with assignment of an overall score. The overall domain scores for each guideline were calculated as outlined in the AGREE II user manual. An initial selection of five random citations was completed, and the reviewers then reviewed and discussed discrepancies.

Guidelines with an overall mean score five or greater were assigned at least moderate quality and included in further analysis. A score below three led to exclusion due to low quality. A score of 3.9 to 4.9 was re-evaluated and inclusion status was decided by consensus. Guideline inclusion status was decided by consensus of three out of four assessors. This generated a list of the high quality guidelines. Across the guidelines the mean scores with standard deviations were reported for each domain score and question. Data were analyzed using STATA 13.1 (Stata Corp. College Station, TX).

1.6.1.4. Synthesis of Evidence

One author (ZG) extracted the guideline characteristics, which were then independently verified by a second author (BM). We report descriptive statistics including: primary conditions covered, region/organizations, number of committee members, numbers of references, and sources of funding. These descriptive statistics were presented across the guidelines to display the breadth of evidence.
Two authors independently extracted the guideline recommendations (ZG, BM). Three authors reviewed the extracted recommendations organized into categories based on their content (ZG, BM and JHL).

1.6.2. Objective 2: Qualitative Study.

We conducted knowledge/end-user focus groups based on the framework of the BCW and content from the above systematic review to assess understanding of high quality guideline recommendations and the barriers/facilitators to their use (134). Incorporating the BCW domains for effective guideline implementation as the underlying theoretical framework results in integration of translational methodology (125). The BCW aids in determination of which translational interventions are appropriate, based on underlying behaviour change domains (125). This allows us to first understand the behaviour, and then map these behaviours to potential interventions for behaviour change. We aim to better understand the barriers and facilitators to the use of these guidelines, and use this knowledge to inform implementation of change. This framework enables systematic analysis of qualitative data, which informs selection of implementation strategies from the BCW.

The systematic review of the multiple CPGs provides a knowledge synthesis of the recommendations for depression or anxiety in patients with dementia and PD, and informs the qualitative portion of this study. Focus groups were used to assess the understanding of CPG recommendations, and the barriers/facilitators to their use by knowledge/end-users (134). Focus groups provide an opportunity for interaction among participants, allowing individuals to reflect upon and respond to ideas expressed by others; this opportunity would not be present if data had been gathered through interview (135). Focus groups have been identified as a useful method of qualitative data collection in vulnerable populations or on sensitive issues, where meeting as a group with similar backgrounds to share experiences is perceived as less threatening (135). Interviews were used to facilitate project completion, where focus groups were not possible. Local ethics approval was received through the Conjoint Health Research Ethics Board, (CHREB-14449) outlined in detail below.

1.6.2.1 Setting, Context & Sampling

Currently in Alberta it is a major cross cutting research objective for the SCNs to address
mood disorders across the continuum of care (136). There has been a focus in all SCNs to address gaps in care for these patients (136). This project falls under the major platform of Aging Brain Care in the Seniors Health SCN (137).

The participants for this study were comprised of two main groups, physicians and patients/caregivers. The inclusion of patients and caregivers as part of the guideline evaluation contributes to early patient engagement, ensuring that findings have a patient oriented focus (138). The recommendations of the guidelines for comorbid depression or anxiety directly effect the care received by patients and caregivers. Therefore, it is key to understand care from their perspectives in order comprehend key barriers and facilitators to guideline use (138). Direct patient and caregiver involvement ensures that further work on the guidelines will include their insights, and implementation strategies will be focused on areas of perceived deficit by end-users (138). Patient oriented research is a key component of the CIHR research strategy. This is discussed in detail in the 2011 document titled, “Canadian Strategy for Patient Oriented Research.” (139). In this document, a proposed solution to the difficulties experienced with knowledge translation is addressed by the important role of the patient to ensure that research priorities are relevant and that the transfer of knowledge is effective. (138).

Focus group recruitment included: primary care physicians; specialists including Geriatricians, Psychiatrists, and Neurologists; participants with PD; and dementia participants and their family caregivers (Figure 2). Descriptions of inclusion criteria and recruitment are below.

All participants spoke English and were able to consent to participation. These groups were chosen to represent the breadth of stakeholders/end-users involved in care of these patients and use of these guidelines. Focus groups were divided by specialty and disease specific groups in order to understand barriers to care from each of the end-user perspectives (Figure 2).
Our sampling frame for patients included all those in the catchment area of the specialty clinics in Calgary. These clinics included Seniors Health (Rockyview General Hospital and Bridgeland Seniors Health), Movement Disorders Neurology (Foothills Medical Centre), General Neurology (South Health Campus), and Cognitive Neurosciences (Foothills Medical Centre and South Health Campus) (Table 2 & 3—Recruitment Plan & Sampling Pool). The focus groups were recruited as a convenience sample based out of the clinics outlined in Table 2 and based on the criterion in Figure 3. This ensures that the sample is based in the relevant clinical context that would be normally encountered as part of patient care.

Recruitment within clinics used strategically placed posters and pamphlets, and staff engagement to handout study information to potential participants. This advertised the study to the entire sampling frame available in Calgary. Recruitment packages (one for patients/caregivers and one for physicians) included a study overview, and an appropriate summary of the systematic review targeted to the end-user group. These materials were disseminated to the local clinics for patient/caregiver recruitment. When potential patients were identified, they were given a recruitment pamphlet with contact information on it.

Some patients were recruited from a prior study by a committee member (NJ). These patients had consented to be contacted about future studies, and were contacted by an independent research assistant with the same recruitment materials placed in the clinic. The
participants contacted the researcher if they wanted to participate in the study.

In all cases, patients contacted the study investigators to participate via phone or email. Once interest had been declared, recruitment materials and eligibility criteria were sent to them. Following self-reported conformation of study criteria, they were recruited. In several cases, potential recruits were self-identified as ineligible based on provided recruitment information.

This method of sampling was chosen to optimize recruitment and feasibility of the study (140). One potential drawback to this type of recruitment is reduced transferability, where the sample recruited does not accurately represent the larger population. To help mitigate this risk, we actively recruited from multiple clinics across Calgary. The catchment area for these specialized serves extends past Calgary to rural southern Alberta; this creates a potential for patients to be recruited from outside of urban Calgary. Patients were included if they had a self reported diagnosis of PD or dementia and concurrent depression or anxiety confirmed by a specialist (Figure 3). Our recruitment in these clinics was focused on patients with dementia who can physically, behaviourally, and verbally participate in a focus group (discussed further below). The consent and recruitment procedures were developed in conjunction with the research team and ethics board.

Table 1. Recruitment Strategy

<table>
<thead>
<tr>
<th>Patient Groups</th>
<th>Specialist Physicians</th>
<th>Generalist Physicians</th>
</tr>
</thead>
<tbody>
<tr>
<td>Seniors Health Clinics</td>
<td>Seniors Health Clinics Location: RGH, Bridgeland Senior’s Health, and South Health Campus (SHC)</td>
<td>Primary Care Networks (PCN) Location: West Central, South Calgary, Foothills and Mosaic.</td>
</tr>
<tr>
<td>Locations: Rockyview General Hospital (RGH) and Bridgeland Senior’s Health</td>
<td>Cognitive Neurology Clinics Location: FMC and SHC</td>
<td>Member Lists: Department of Family Medicine, Division of Geriatric Medicine</td>
</tr>
<tr>
<td>Cognitive Neurology Clinics Location: Foothills Medical Centre (FMC) and SHC</td>
<td>Movement Disorders Clinics Location: FMC</td>
<td>Member Lists: Seniors Health SCN and Addictions and Mental Health SCN</td>
</tr>
<tr>
<td>Movement Disorders Clinics Location: FMC</td>
<td>Geriatric Psychiatry &amp; Neuropsychiatry</td>
<td>Geriatric Psychiatry &amp; Neuropsychiatry</td>
</tr>
<tr>
<td>Geriatric Psychiatry &amp; Neuropsychiatry</td>
<td></td>
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</tr>
<tr>
<td>Locations: FMC, RGH &amp; Sheldon Chumir Centre</td>
<td>Locations: FMC, RGH &amp; Sheldon Chumir Centre</td>
<td></td>
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<tr>
<td>---------------------------------------------</td>
<td>---------------------------------------------</td>
<td></td>
</tr>
<tr>
<td>Member Lists: Departments of Neurology, Psychiatry, Section of Geriatrics, Seniors Health and Addictions &amp; Mental Health SCN</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Given the nature of cognitive impairment, difficulty with participation was a concern. We incorporated the recommendations for including dementia patients in qualitative studies as outlined by Murphy et al. (141). These include recognition that capacity is context-specific, inclusion should not be based on a screening tool and a surrogate should be included (141).

The sampling frame for physicians included all of those working in the previously mentioned specialty clinics, and FPs. FPs were recruited through the Care of the Elderly groups, Family practitioner email lists and Primary Care Networks. We recruited approximately six to eight physician participants per focus group, which culminated in the formation of five groups (Geriatric Medicine, Geriatric Psychiatry, Movement Disorders, Cognitive Neurology & Family Practitioners). FPs with the Care of the Elderly designation, or FPs practicing in assisted living and long-term care facilities were more likely to have a representative patient population, and were preferentially recruited over other FPs. In all cases, physicians were identified from local contacts, and department and SCN lists. Physicians recruited met the criteria described below and in Figure 3. Recruitment was achieved through both purposive and snowball sampling. The specialists included have regular exposure to these patient populations. FPs were included if they had experience with at least one patient with PD or dementia and a comorbid depression or anxiety in the past 18 months (Figure 3).

Focus groups took place on site at the University of Calgary Health Sciences Centre adjacent to the Foothills Medical Centre in Calgary, Alberta. The HSC was an easily accessible and well-outfitted facility where multiple studies occur.

1.6.2.2. Data Collection

The preceding systematic review informed the development of an interview guide, providing evidence and recommendations for best practice. This study focused on the implementation of evidence based CPGs, and the interview guide incorporated the TDF. The
initial discussion guide focused on the 14 domains of the TDF outlined in Appendices C & D. Questions posed fell within TDF domains Appendix G. This enabled data collected to be readily mapped back onto the BCW, and linked directly to relevant interventions for the identified barriers (125, 126).

The discussion guides for both physicians and patients included broad sections on diagnosis and management of anxiety or depression. Physician groups had a separate section, focusing on barriers and facilitators to guideline use. The focus group guides below (Appendices C & D) were approved by CHREB, and only minor clarifications to certain questions were added after the initial focus group. These served to clarify the word “skills” in two questions. The initial broad opening question was left out of the expert groups, it did not add value to more focused questions. These minor adjustments were reviewed and agreed upon by JHL and HH.

One researcher (ZG) facilitated all focus groups with a co-facilitator (JHL or HH). One researcher completed all interviews independently (ZG). The co-facilitator was responsible for recording field notes on the participants’ interactions and content of discussion. Field notes aided in bracketing researcher bias and expectations but also to provide the context of the discussion (142). The facilitator reported a brief verbal summary to the group as a concurrent member check (143). De-briefing notes were recorded by the facilitator and reviewed by the co-facilitator (JHL or HH).

**Figure 3. Inclusion Criteria**

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| Inclusion Criteria Specialist Physicians | • Must have regular experience providing care for patients with Dementia or PD and Comorbid Mood Disorder in their Practice |
| Inclusion Criteria General Practitioners | • Must have experience providing care for at least one patient with Dementia or PD and Comorbid Mood Disorder in their Practice within the past 18 months |
| Inclusion Criteria Patients & Caregivers | • A carer or patient with Dementia or PD with a Mood Disorder (As Diagnosed by Specialist)  
• Able to provide informed consent or proxy consent.  
• Verbally, physically, and functionally able to participate in a Focus Group |

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27
All FG and interviews were audio recorded and transcribed verbatim by ZG or MK. This information in the transcripts was anonymized. Once complete transcriptions were reviewed and verified by ZG with the audio recordings and field notes.

1.6.2.3. Data Analysis

A framework approach (Figure 4) was used for analysis. Framework analysis was developed to specifically focus on the generation of practice oriented findings (135). This is applicable in this situation where we aim to use the understandings from the focus groups to develop behaviour change interventions. This analysis is defined as a content analysis method, which involves summarizing and classifying data within a thematic framework (135). This works well with the chosen frameworks of behaviour change in the TDF and BCW. A key component of this analysis is the comparability across cases and within cases (144).

This analysis follows the stages of familiarization, identifying themes, indexing, charting, mapping, and interpretation (144, 145). This process was completed between three researchers (ZG, HH, JHL). First, the researchers familiarized themselves with all data (recordings, transcripts, field and debriefing notes) and recorded initial thoughts (144, 145). Next was identification. ZG coded the data line by line, with JHL and HH performing validation coding on 20% of the first half of transcripts (144, 145). High correlation among all researchers during initial coding negated the need for further validation coding. Coding was reviewed multiple times: after the initial transcription, with the audio file, after coding of other groups, and then twice after all data was collected. This ensured that coding was comprehensive. All focus group transcripts and detailed coding with quotes were provided to JHL and HH to review. This process allowed development of themes from the focus groups and research questions (144, 145). All codes were grouped into categories according to the theoretical framework (indexing) initially by ZG, and then reviewed in detail by the research team. The team also met to discuss the meaning and context of these codes and how they should be categorized (144, 145). Discrepancies in coding between researchers were resolved by discussion (144, 145). All codes were included, even if they did not fit into the framework to avoid exclusion of potentially relevant data or outliers (144). Charting took place to arrange the data by category in the framework and transcript by ZG (144). This was checked over three times, and reviewed by JHL and HH. Codes were further broken down into barriers and facilitators within each category.
This enabled mapping across concepts and interpretation to take place across the breadth of the data transcripts and framework categories (144, 145). This last interpretive step generated understanding, concepts, notable associations, and developed explanations for findings (144). This was developed through continued discussion with the research team ZG, JHL & HH (144). The reported practices of physicians were compared with guideline recommendations to evaluate alignment (extracted by ZG, reviewed by JHL & HH)

1.6.2.4. Data Handling

Each focus group or interview was recorded digitally and transcribed verbatim. Transcription was completed by a secretary and ZG. Transcripts were anonymized (including names, locations etc.), and identifying data was removed. Transcripts were verified by ZG for accuracy.

All original audio files were saved and backed up on secure drives, providing an ongoing data trail, authenticity, and a back check. Field notes were scanned and debriefing notes were typed out and saved digitally. All hard copies were eliminated in confidential recycling through Iron Mountain©. Data was saved on firewalled, virus/surge protected, password protected, and Alberta Health Services (AHS) network secure USB drives and a private drive within the AHS network server, where access is limited to the research team. All data was appropriately labelled and dated to ensure clarity version control. The data was only accessed on secure computers, and no information was saved outside of the secure drives. The data was restricted to the research team responsible for analysis. The data was organized during analysis using NVIVO (NVivo qualitative data analysis software; QSR International Pty Ltd. Version 10. 2014).

All information was kept confidential in accordance with the rules and regulations of the University and CHREB. These data were not linked to any other study. All data was stored in a form suitable for long-term preservation in keeping with standards of data retention. All original and analyzed data were backed up on a separate secured drive within the AHS network server. All hard copy consent forms were scanned and stored digitally. All hard copies were retained as required. Hard copies were kept separate from digital data to avoid association and potential identification. All data was stored only on site in an AHS facility in locked filing cabinets and restricted access offices.
1.6.2.5. Ethical Considerations (CHREB ID: REB 14-1449)

Local ethics approval was acquired through the local CHREB. All interview guides and recruitment materials were submitted for review. We obtained informed written consent from all study participants prior to involvement in focus groups. All participants were made aware at the time of consent and initiation of focus groups of their rights to autonomy, and the right to leave or opt out at any time. Participants also had the right to request that their contributions not be used. All participants signed consent and confidentiality agreements. All data (transcriptions, field notes, debriefing notes) were kept confidential in keeping with the policies of the CHREB and University. All data handling procedures are outlined above.

Discussion of depression, anxiety and neurologic diseases could be sensitive or difficult for some participants. Contacts for support services were made available to study participants as required.
Figure 4. An Outline of Framework Analysis. Adapted from Gale et al. and Pope et al. (144, 145)
2.1 Abstract

Background: Depression and anxiety remain under-diagnosed and under-treated in those with neurologic diseases such as dementia or Parkinson’s Disease (PD).

Objectives: First, to provide a synthesis of high quality guidelines available for the identification and management of depression or anxiety in those with dementia or PD. Second, to identify areas for improvement for future guidelines.

Methods: We searched MEDLINE, PsycINFO, and EMBASE (2009 to July 24, 2015), grey literature (83 sources; July 24-Sept 6, 2015), and bibliographies of included studies. Included studies were evaluated for quality by four independent reviewers the AGREE II tool. Guideline characteristics, statements and recommendations relevant to depression or anxiety for dementia and PD were then extracted.

Results: 8121 citations were reviewed with 31 full text articles included for assessment with the AGREE II tool. 17 were of sufficient quality for inclusion. Mean overall quality scores were
between 4.25 to 6.5. Domain scores were lowest in the areas of stakeholder involvement, applicability, and editorial independence.

Recommendations for the screening and diagnosis of depression were found for PD and dementia. There was little evidence to guide diagnosis or management of anxiety. Non-pharmacologic therapies were recommended for dementia patients. Most advocated pharmacologic treatment for depression, for both PD and dementia, but did not specify an agent due to lack of evidence.

**Conclusion:** The available recent high quality guidelines outline several recommendations for the management of comorbid depression or anxiety in PD or dementia. However there remain significant gaps in the evidence.

**2.2. Introduction**

Persons experiencing neurologic disorders, such as dementia or Parkinson’s disease (PD), and depressive or anxiety disorders have poorer outcomes with reduced quality of life, poor functional status and worsened cognition (8, 13, 16, 19, 82, 146-148).

It is estimated that the prevalence of depression in dementia is approximately 25% with anxiety occurring in up to 75% (7-9, 12). In PD, approximately 17% of patients experience major depression and anxiety between 3.6 to 40% (16, 17).

Despite awareness of these comorbidities, depression and anxiety remain under-diagnosed and under-treated in those with neurologic diseases (5, 13, 18-22). Only 20% of PD patients diagnosed with depression receive therapy (23). This represents a significant knowledge-to-practice gap. One way to address this is through the use of Clinical Practice Guidelines (CPGs)(30). CPGs synthesize available evidence based on a systematic review of the literature, clinical expertise and patient preferences (30). CPGs are targeted at practitioners who apply the recommendations to clinical decision-making and reduce disparities in care (30, 87-89).

Thus, in the setting of PD and dementia, CPGs should enable the appropriate management of depression and anxiety (38-41). Despite available CPGs, these disorders remain under-managed, suggesting these CPGs are underused or lack sufficient recommendations (41-43). Multiple available guidelines of varied quality leads to uncertainty as to which CPGs should be used in practice. Our primary aim is to synthesize the high-quality evidence-based CPGs available for diagnosis, and management of depression or anxiety in those with dementia or PD.
Secondarily we aim to, identify areas gaps within the existing guidelines to inform future guideline development.

2.3. Methods

The study protocol follows the recommendations provided by the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) -Protocols Statement and guidelines (149) and the protocol was registered with PROSPERO (32) (CRD: 42016014584).

Search Strategy

The literature search was developed in conjunction with an experienced librarian (DL) and was verified independently by a second librarian (HLR), using the Peer Review of Electronic Search Strategies (PRESS) methodology (131). Any recommendations were incorporated into the final search.

Databases included MEDLINE, EMBASE, and PsycINFO. Clusters of terms (controlled vocabulary and key words) were used to search each database; these include dementia, Parkinson’s disease, depression, anxiety and CPGs (Appendix A & Box 2). The search was completed by cluster, first searching the terms in each cluster (combined with the Boolean operator ‘OR’) and keyword searches of abstracts and titles. The clusters were then combined with ‘AND’. We searched for several pathological variants of dementia including Alzheimer’s disease, vascular, frontotemporal, Lewy Body disease, Huntington’s Disease, CADASIL, primary progressive aphasia, and Creutzfeldt Jakob (Appendix A). We included relevant derivatives of terms or broad key words related to depressive or anxiety disorders (Appendix A).

This was augmented by a search of the grey literature (Table 6). This search was limited from 2009 to search date, such that we would only capture CPGs developed within the past 5 years; given the evidence that CPGs may become out of date after only 3 years (132). All languages were included in this search.

Selection & Eligibility

All citations were reviewed for eligibility by two independent authors; citations meeting initial eligibility criteria were included in full text review. If there was disagreement at the abstract stage, the full article was pulled for review. Bibliographies for all included articles were
searched. If multiple CPGs were identified from a single agency on the same topic the most recent was used.

At the first stage of abstract review, any article that represented a guideline for PD or dementia was included. Eligibility at the full text stage required that the CPGs included at least one recommendation related to depression and/or anxiety in patients with PD and/or dementia. The kappa statistic was used to quantify inter-rater reliability.

For non-English articles that met eligibility at the full text stage, the language was determined using online translation software. Citations were translated using the online (Google translate) function to determine if an article was a guideline. When included, the documents were searched using translated relevant terms; for example, if a guideline pertained to PD in the abstract, the text was searched for depression or anxiety (and all translated synonyms). If those criteria were met, the full guideline was translated and reviewed.

Assessment of Quality

The Appraisal of Guidelines Research & Evaluation (AGREE II) tool was used to assess guideline quality (Appendix B) (133). This tool was designed to evaluate guideline quality and to aid in guideline development and reporting (133). The tool includes 6 domains covering scope and purpose, stakeholder involvement, rigour of development, clarity of presentation, applicability and editorial independence (133). Within each domain there are between 2 to 8 questions, to a total of 23 (133). Each item is rated from 1 (not included or very poorly reported) to 7 (exceptional reporting of all criteria outlined in the AGREE II Manual)(133).

Each domain was scored independently by four reviewers, along with the assignment of an overall score. An initial assessment of 5 citations was done and compared across all 4 reviewers. The 4 reviewers met to discuss discrepancies and address questions about rating, before the remainder of the guidelines were reviewed and scored. This also served to ensure that all raters were aligned in their understanding of the AGREE II items. Any further discrepancies were resolved by discussion.

Domain scores pooled across the 4 assessors were calculated, as outlined in the AGREE II user manual. The higher score indicates a higher quality across rated items. It has been demonstrated that the quality across the AGREE II domains predicts guideline implementation (133). The mean overall quality scores with standard deviations (SD) were calculated, as well as
for each domain item. CPGs with a mean overall quality score 5 or greater were assigned at least moderate quality and included in further analysis. CPGs with a score below 3 were excluded due to low quality. A score less than 5 but greater than 3 were re-evaluated and inclusion status was decided by consensus.

Data Extraction & Synthesis of Evidence

Guideline characteristics were extracted by one author (ZG) and independently verified by a second author (BM). Items extracted included the primary conditions covered, region/organizations, number of committee members, numbers of references, and sources of funding.

Two independent reviewers then extracted relevant recommendations (ZG, BM). Specifically, guidelines were searched for any mention of relevant recommendations and supporting text or statements. Three authors reviewed the extracted recommendations (ZG, BM and JHL). Recommendations were compiled across the guidelines into relevant categories and subcategories, and reported using descriptive statistics including the quality, number of guidelines supporting the statement and subpopulations included. As the evidence in the guidelines is represented by practice recommendations, it was not amenable to meta-analysis. The main output of this systematic review was an appraisal of the quality of all guidelines pertaining to comorbid depression or anxiety in PD or dementia, and a synthesis of the recommendations across the different guidelines. Data were analyzed using STATA 13.1 (Stata Corp. College Station, TX).

2.4. Results
Study Selection

The database search generated 4441 citations after duplicates were removed, with a further 3681 citations identified from the grey literature (Figure 5). When screened for eligibility, 360 citations met criteria for full text review (κ=0.88, 95.7% agreement). At this stage most articles were excluded because they were not relevant (n=218), were not guidelines, or were unrelated guidelines. Other common reasons for exclusion at the full text stage were being out of the date range (n=33) or a duplicate (n=35). Excluded citations also included 26 mental health guidelines that did not address PD or dementia. Similarly there were 5 PD and 9 dementia
guidelines that did not address depression or anxiety. The dementia guidelines primarily pertained to Alzheimer’s disease, vascular dementia, general dementia care and one referred to Lewy Body Disease. Of these articles, 4 were identified to be summary documents of included guidelines and were used as supplemental material to these included guidelines. Twenty-six CPGs met all eligibility criteria and were evaluated using the AGREE II tool, of which 17 met the quality cut off for inclusion.

**Guideline Characteristics**

The 17 included guidelines addressed PD (n=5), dementia (n=8) and mental health (n=4) CPGs (Table 2). They included recommendations from many regions, including Canada (n=2), USA (n=3), Pan-European (n=4), UK (n=2), Scotland (n=1), Spain (n=2), South Korea (n=1) and international (n=2). The associations or organizations are outlined in table 2. All guidelines used a method for grading the evidence (Figure 6). Most guidelines were funded through government or non-commercial funding; only two CPGs had some pharmaceutical funding.

**Study Quality**

These 26 CPGs were assessed for quality using all 23 items across the 6 domains of the AGREE II tool. Nine guidelines were excluded for low quality. Six were excluded with an overall mean rating ranging from 2.25-3.75. Three had ratings of 4-4.5, where decision to exclude was by consensus. A low rating was typically due to unclear methods; thus scoring low on rigour of development, applicability and editorial independence. Authors of guidelines were contacted for more information in the case that an item was unclear and responses were incorporated in the quality assessment.

The 17 included guidelines had mean overall scores from 4 to 6.5 (Table 3). When examining the individual domain scores, the highest rated domain was Domain 4: Clarity of Presentation (mean score 77.0; SD 11.4). This was followed by Domain 1: Scope and Purpose (mean score 72.1; SD 12.1). Domain 5: Applicability was the lowest rated domain (mean score 41.5; SD 22.6). Stakeholder involvement (Domain 2) also had a low score (mean score 54.5; SD 23.3).

The mean rating across each question in the domain scores were also examined to explore differences between domains (Table 7). Question one pertaining to the overall objectives was the
highest rated item at 5.88 (SD 0.61), followed by link between evidence and recommendations at 5.78 (SD 0.51). The lowest rated item was providing a procedure for updating the guideline is provided, with a mean rating of 3.16 (SD 1.73). The views and preferences of the target population have been sought was also rated poorly with a mean score of 3.25 (SD 1.92). All items in Domain 5 had low mean scores, ranging between 3.27 (SD 1.46) for resource implications and 3.72 (SD 1.53) for advice on putting recommendations into practice.

Guideline Recommendations

The details of extracted recommendations are summarized in the Table 4 for PD and Table 5 for dementia. 21 categories of recommendations were extracted in total.

Parkinson’s Disease Recommendations

Only two guidelines discussed anxiety in those with PD (150, 151). These stated there was little evidence for either the diagnosis or treatment of anxiety in PD, and that there was insufficient evidence for the treatment of anxiety with levodopa.

There were clear recommendations surrounding the diagnosis of depression in PD (150, 152, 153). Clinicians should have a low threshold for the diagnosis of depression in PD given the difficulties making a diagnosis (150). Use of a validated tool for detecting depression (or neuropsychiatric symptoms) was advocated by two guidelines, with varying levels of recommendations (152, 153). Tools that were recommended include the HDRS, the MADRS or the UPDRS– Part 1 Non-Motor. The diagnosis should be made based on a clinical interview and not based on the tool alone and should seek collateral information from carers.

Antidepressant therapy is recommended, however there is little evidence to support one agent over another (n=2) (152, 154). Additionally, the choice of an agent must be individualized (n=1) and the practitioner should consider side effects and drug interactions prior to initiation (150). There have been prior studies on the tricyclic antidepressants (TCAs), specifically amitriptyline, and although they were beneficial for mood, this was offset by the side effects (n=3) (150, 152, 154). One guideline noted that selective serotonin reuptake inhibitors (SSRIs) showed some benefit in uncontrolled studies (154, 155), but noted that the SSRIs could worsen PD symptoms of restless legs (RLS), periodic limb movement (PLM) and REM sleep behaviour.

Appendix C & D have the extraction with direct quotes from guidelines.
disorder (RBD) (n=2) (154, 155). It is recommended to avoid amoxapine and lithium in those with PD, due to the risk of worsening motor symptoms (n=1)(154).

There is some weak evidence supporting the use of dopamine agonists and monoamine oxidase inhibitors for the management of depression in PD (n=3)(150, 154, 155). Pramipexole was suggested to have an antidepressant effect not solely due a motor effect (155). Selegiline has some antidepressant effects but further studies are needed (154). If the mood symptoms are only present during off periods, it was suggested that patients might benefit from drugs addressing the motor symptoms. However there was no evidence levodopa alone affected mood.

Other therapies for depression are not well explored in PD. The European Federation of Neurological Sciences (EFNS) concluded there was insufficient data to recommend psychotherapy, electroconvulsive therapy (ECT) or transcranial magnetic stimulation (TCMS)(155). Other guideline assert that ECT has been used in PD, but that there are no specific trials in PD and is associated with risk (n=2)(150, 154).

Dementia Recommendations

It is recommended that patients with dementia be assessed for anxiety (n=2), however there is no clear consensus on what tools to use (138, 156). One guideline recommended the use of the Hospital Anxiety Depression Scale (156). The evidence for the treatment of anxiety in dementia is lacking (n=1)(156).

It is recommended that patients with dementia be evaluated and re-evaluated over time for depression (n=5)(36, 138, 156-158). As part of this assessment, patients should be evaluated for other causes of depression (e.g. medications, bereavement etc.). It is suggested that these patients be assessed for suicidality by one guideline (154), however another reported there was inconclusive evidence regarding this (159).

The use of a valid screening tool was recommended for depression case finding (n= 5) in dementia, including the CSDD, GDS or Dementia Mood Assessment Scale (DMAS) (36, 154, 156, 160, 161). The CSDD was more commonly recommended given it is a clinician-rating tool that involves caregivers with higher sensitivity (n=4) (36, 154, 160, 161).

Therapy for depression in those with dementia should include a variety of non-pharmacologic options (n=4) such as stimulation oriented, cognitive behavioural, reminiscence, exercise or multi-sensory therapy (138, 154, 156, 161). Pharmacologic therapy is recommended
despite variable evidence (n=6)(36, 138, 156, 158, 162, 163). It is suggested by one guideline that, if there is no improvement with non-pharmacologic therapy, an antidepressant be considered (163). Another notes that for moderate-severe depression, pharmacologic treatment is warranted (n=1)(162). However, there needs to be a clear risk-benefit assessment and discussion (n=1)(138). Based largely on clinical experience, most guidelines recommend the use of SSRIs given the lower side effect profile over TCAs (n=6)(36, 138, 154, 156, 162, 163). The concern with TCAs is largely anticholinergic side effects causing worsened cognition. Other antidepressants such as mirtazapine, bupropion, and venlafaxine may also be of benefit (n=1). Other adjunct therapies recommended include stimulants (n=2)(154, 156), cholinesterase inhibitors (n=1)(156) and ECT on a case-by-case basis (n=1)(154).

2.5 Discussion

This study provides a synthesis and quality assessment of available guidelines for the management of depression or anxiety in PD or dementia. We identified clear gaps in guideline quality and the evidence, which inform future research and knowledge translation.

Guideline Quality

Guidelines that were excluded due to low quality were typically those that lacked explicit development methods, thus ratings across all the domains were low. When examining the AGREE II ratings overall, the lowest rating was in assessing the guideline description of barriers and facilitators, implementation, resource implications, or monitoring/auditing criteria (Domain 5). In fact, few guidelines had discrete sections addressing knowledge translation. The concern about guideline applicability was explored in a 2015 systematic review (95), which found that applicability scored lower than any other domain (95, 164). If guidelines rarely address their implementation in practice, then there will be continued practice variation. There is clear evidence supporting the use of implementation tools to improve guideline uptake (95). Thus making guidelines without a clear knowledge translation plan does a disservice to stakeholders.

The engagement of patients and caregivers was notably absent in CPG development. This process is important, as it is aimed at improving implementability, by ensuring the recommendations are comprehensive, adaptable and applicable to the target group and have an open process (92). Given the constant changing nature of evidence, having up-to-date guidelines
certainly makes a difference to the validity (132). However, the lowest rated item was for the guideline update procedures.

**Guideline Content**

There is an overall lack of recommendations related to the diagnosis or treatment of anxiety in either PD or dementia. This stems from the fact there is little evidence on how to approach the assessment. One guideline suggested the use Hospital Anxiety and Depression Scale for dementia, but they did not provide diagnostic accuracy information or suggestions for implementation (156). There is also a concern that the medications traditionally used for anxiety can have major adverse effects (151), and there are few studies to guide treatment. Anxiety was less frequently mentioned than depression in the included CPGs, and in some cases was only mentioned in combination with other neuropsychiatric symptoms. The overall lack of evidence for anxiety care in PD and dementia is a major gap in the current research.

Guidance for depression was present in a higher proportion of guidelines. Despite this, there is variability in the reporting of levels of evidence and recommendations (Figure 6). In some cases the recommendations for depression in PD only had 1 or 2 guidelines supporting them, indicating variance in guideline reporting. In other cases recommendations were vague, which can lead to difficulty with end user interpretation and implementation.

It is clear that screening for depression with a validated tool in PD is recommended, although evidence varies. It is recommended, as a good practice point, that any diagnosis of depression is not made solely on a brief assessment tool, as these tools are more focused on case finding (152). Although this is an important concept in detection, it was only recommended by one guideline (165). A 2015 systematic review identified several validated tools for the detection of depression in PD, with the GDS-15 having the highest pooled sensitivity (0.81; 95% CI 0.64, 0.91) and area under the curve (0.94)(66).

Recommendations surrounding non-pharmacologic therapy were few, stating there was insufficient evidence for the use of psychotherapy, ECT or TMS. Two recent trials demonstrated the effectiveness of CBT in PD (72, 73). This highlights the need for further large high quality studies on a range of non-pharmacologic therapies and the need for constant update of guidelines. Pharmacological therapy is recommended for managing depression in PD, but there
is little evidence on choosing agents (154, 165). This has resulted in a variety of treatment recommendations, with little evidence to direct clinical practice.

Depression in dementia was more frequently addressed. However, these recommendations also had varied guideline and evidentiary support. Guidelines supported the evaluation of depression in dementia, but evidence ranged from high quality to good practice points. Commonly recommended tools were the CSDD and GDS, with preference towards the CSDD due to better accuracy (36, 154, 156, 160, 161). This was confirmed by a 2015 systematic review of depression tools for dementia, finding that the CSDD had a area under the curve of 0.89 (69).

Interestingly, the issue of evaluating for suicide risk was raised in two guidelines with divergent recommendations. One stating there was inconclusive evidence (159) and another stating substantial evidence (154). It is unclear why there is such a difference in reported evidence; perhaps development groups have different evidence available or differing interpretations of the evidence.

There are stronger recommendations for non-pharmacologic treatment in dementia than in PD, outlining several options (36, 138, 156, 160, 161). The evidence for pharmacologic therapy is described as mixed with Grade 2A (Moderate Recommendation, High Level Evidence) to Class IV (Un-blinded Study, Expert Opinion) (36, 138, 154, 158, 162, 163). Again SSRIs and TCAs are the focus, with TCAs being less likely to be recommended due to side effects (36, 154, 156, 160, 163). For those with dementia, there were more options recommended for therapy including stimulants, cholinesterase inhibitors and ECT (154, 156).

2.6. Limitations
There is a well-recognized issue with heterogeneity in the terms used to refer to guidelines. For our database search we used indexed terms from each of the three databases as well as key words using known nomenclature for guidelines and the comorbidities. It is also possible that the addition of the depression or anxiety criteria to the search may have been restrictive, however without these terms the search was impractical. To address this, we developed the search strategy with experts in the area of guideline systematic review and an experienced librarian, and we had an external reviewer independently assess the search strategy.
To reduce the risk of missing literature not indexed in databases we contacted experts, searched references of included studies and performed an extensive search of the grey literature search.

2.7. Conclusions
Given the burden of comorbid mental illness in dementia and PD, it is key that we understand clearly the current knowledge base so we can improve care for these populations. This study provides a synthesis and quality assessment of the relevant guidelines. By synthesizing the recommendations, we identified areas of knowledge that are potentially ready to be translated into practice but also clear evidence gaps. This data was further evaluated in a subsequent study by stakeholders in focus groups to understand the other barriers and facilitators to the use of guidelines. This was to inform and help develop a comprehensive knowledge/end-user focused plan for addressing these gaps.

2.8. Acknowledgements
The authors would like to thank Diane Lorenzetti MLS, Research Librarian (DL) for her input into the search strategy, and Helen Lee Robertson MLIS, Liaison Librarian for Clinical Medicine for her (Peer Review of Electronic Search Strategies) PRESS review of our search strategy.

2.9. Authors’ Roles
ZG and BM performed all citation/full text screening, quality assessments, data extraction and analysis and drafted the manuscript. ZG completed all statistical analysis. SG was involved in the grey literature search and quality assessment. JHL supervised all parts of the systematic review and analysis, was involved in the quality assessment and determination of inclusion. ZG, BM, SG, HH, SS, TP, NJ and JHL provided input and reviewed the proposal, protocol, analysis and manuscript. ZG registered the protocol with PROSPERO (166). All authors had access to the data, reviewed and approved the final manuscript. ZG and JHL had full access to the data in the study and take responsibility for the integrity of the data and accuracy of the data.
2.10. Figures & Tables

Figure 5. PRISMA Flow Diagram

Records identified through database searching

July 24, 2015
EMBASE 3617, MEDLINE 1376,
PsycINFO 857
(n= 5850)

Additional records identified through other sources

July 24-September 6, 2015
83 Sources (See Table 1)
(n = 3681)

Records after duplicates removed (Database n= 4441) (Grey Literature n=3681)

Records screened (n = 8122)

Records excluded (n = 7762)

Full-text articles assessed for eligibility (n = 360)

Studies included in qualitative synthesis (AGREE II Assessment) (n=26)

Used in Conjunction with Primary Guideline Document (n=5)

Studies included in quantitative synthesis (n = 17)

Full-text articles excluded, with reasons (n = 329)
1. Unobtainable = 3
2. Duplicate = 35
3. Not Relevant = 218
4. Out of Date Range = 33
5. PD Guideline without depression or anxiety = 5
6. Dementia Guideline without depression or anxiety = 9
7. Depression or Anxiety guideline without PD or dementia = 26

Excluded for Low Quality (n=9)
Table 2. Guideline Characteristics

<table>
<thead>
<tr>
<th>Author</th>
<th>Organization</th>
<th>Primary Condition¹</th>
<th>Focus</th>
<th>Region of Origin</th>
<th>Number of Committee Members⁸</th>
<th>Number of References</th>
<th>Systematic Search Strategy (Y/N)</th>
<th>Grading of Evidence (Y/N)</th>
<th>Funding (NS, P, NC, G)⁹</th>
<th>Mean Quality Score</th>
</tr>
</thead>
<tbody>
<tr>
<td>No Author (2010)²</td>
<td></td>
<td>PD</td>
<td>Diagnosis</td>
<td>Scotland</td>
<td>20</td>
<td>189</td>
<td>Y</td>
<td>Y</td>
<td>G</td>
<td>6</td>
</tr>
<tr>
<td>Grimes et al. (2012)³</td>
<td>FILTERED</td>
<td>PD</td>
<td>Diagnosis</td>
<td>Canada</td>
<td>22</td>
<td>62</td>
<td>Y</td>
<td>Y</td>
<td>NC &amp; P</td>
<td>6.5</td>
</tr>
<tr>
<td>Berardelli et al. (2013)</td>
<td>European Federation of PD</td>
<td>Diagnosis Europe</td>
<td>25</td>
<td>245</td>
<td>Y</td>
<td>Y</td>
<td>NS²</td>
<td>5</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Ferreira et al. (2013)</td>
<td>European Federation of PD</td>
<td>Treatment Europe</td>
<td>22</td>
<td>363</td>
<td>Y</td>
<td>Y</td>
<td>NC</td>
<td>4.5</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

¹ PD: Parkinson's Disease
² No Author (2010)
³ Grimes et al. (2012)
⁴ Berardelli et al. (2013)
⁵ Ferreira et al. (2013)
⁶ Number of Committee Members
⁷ Systematic Search Strategy
⁸ Grading of Evidence
⁹ Funding
⁰ Mean Quality Score
<table>
<thead>
<tr>
<th>Author</th>
<th>Organization</th>
<th>Topic</th>
<th>Region</th>
<th>Year</th>
<th>Range</th>
<th>No. of Cases</th>
<th>Y is Diagnosis</th>
<th>Y is Treatment</th>
<th>Score</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hort <em>et al.</em> (2010)</td>
<td>European Federation of Neurological Societies (EFNS)</td>
<td>Alzheimer’s Dementia Diagnosis Treatment</td>
<td>Europe</td>
<td>8</td>
<td>100</td>
<td>Y</td>
<td>Y</td>
<td>NC</td>
<td>4.25</td>
</tr>
<tr>
<td>No Author (2010)</td>
<td>Ministry of Health, Social Services and Equality &amp; Agency for Health Quality and Assessment of Catalonia (AQuAS) National Institute for Health and Care Excellence, National Collaborating Centre for Mental Health</td>
<td>Dementia Diagnosis Treatment</td>
<td>Spain</td>
<td>67</td>
<td>688</td>
<td>Y</td>
<td>Y</td>
<td>NC &amp; G</td>
<td>5.75</td>
</tr>
<tr>
<td>No Author (2011)</td>
<td>National Institute for Health and Care Excellence, National Collaborating Centre for Mental Health</td>
<td>Dementia Diagnosis &amp; Treatment</td>
<td>UK</td>
<td>28</td>
<td>NN</td>
<td>Y</td>
<td>Y</td>
<td>NC &amp; G</td>
<td>6.5</td>
</tr>
<tr>
<td>Author(s)</td>
<td>Institution(s)</td>
<td>Topic</td>
<td>Country</td>
<td>Year</td>
<td>Cite</td>
<td>Y/N</td>
<td>Y/N</td>
<td>NC/P</td>
<td>Score</td>
</tr>
<tr>
<td>-----------</td>
<td>--------------------------------------------------------------------------------</td>
<td>-------</td>
<td>---------</td>
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<td>------</td>
<td>-----</td>
<td>-----</td>
<td>------</td>
<td>-------</td>
</tr>
<tr>
<td>Ihl et al. (2011)</td>
<td>British Psychological Society &amp; The Royal College of Psychiatrists (NICE) World Federation of Societies of Biological Psychiatry (WFSBP) Clinical Research Centre for Dementia (CRCD)</td>
<td>Dementia Treatment International</td>
<td></td>
<td>39</td>
<td>215*</td>
<td>Y</td>
<td>Y</td>
<td>NC</td>
<td>4.5</td>
</tr>
<tr>
<td>No Author (2011)</td>
<td></td>
<td>Dementia Diagnosis South Korea</td>
<td></td>
<td>20</td>
<td>NN⁷</td>
<td>Y</td>
<td>Y</td>
<td>G</td>
<td>5.25</td>
</tr>
<tr>
<td>O'Brien et al. (2011)</td>
<td>British Association of Psychopharmacology (BPA) European Federation of Neurological Societies &amp; European Neurological Society (EFNS-ES)</td>
<td>Dementia Treatment UK</td>
<td></td>
<td>16</td>
<td>148*</td>
<td>N</td>
<td>Y</td>
<td>NC &amp; P</td>
<td>4</td>
</tr>
<tr>
<td>Sorbi et al. (2012)</td>
<td>European Federation of Neurological Societies &amp; European Neurological Society (EFNS-ES)</td>
<td>Dementia Diagnosis Treatment Europe</td>
<td></td>
<td>17</td>
<td>189</td>
<td>Y</td>
<td>Y</td>
<td>NC</td>
<td>4.5</td>
</tr>
<tr>
<td>Gautier et al (2012)⁵</td>
<td>Canadian Consensus Conference on the Diagnosis</td>
<td>Dementia Diagnosis Treatment Canada</td>
<td></td>
<td>38</td>
<td>19</td>
<td>Y</td>
<td>Y</td>
<td>NC</td>
<td>5.5</td>
</tr>
</tbody>
</table>
1. Dementia guidelines primarily included Alzheimer’s disease, vascular dementia, general dementia care and one referred to Lewy Body Disease.

2. Includes Grosset et al. 2010 (165)

3. Includes Patel et al. 2014 (167)


5. Includes Moore et al. 2014 (37), Herrman et al. 2013(168)

* Number counted from the text
6. Includes Recommendations Referenced in Rabin et al. (169)
7. NS: Not Stated, NN: Not Numbered
8. Committee members - extracted from paper as listed (e.g. authors listed, guideline development/working groups etc.)

**References:** The American Academy of Neurology (AAN) (151), Scottish Intercollegiate Guidelines Network (SIGN) (152, 165), Canadian Neurological Sciences Federation (CNSF) (150), Parkinson’s Society Canada (150), European Federation of Neurological Societies (EFNS) (n=4) (36, 153, 155, 160), Movement Disorders Society-European Section (MDS-ES) (153, 155), National Institute for Health and Care Excellence (NICE) (170), Ministry of Health, Social Services and Equality & Agency for Health Quality and Assessment of Catalonia (AQuAS) (171), British Psychological Society (170), The Royal College of Psychiatrists (170), World Federation of Societies of Biological Psychiatry (WFSBP) (158), Clinical Research Centre for Dementia (CRCD), British Association of Psychopharmacology (BPA) (172), European Neurological Society, Canadian Consensus Conference on the Diagnosis and Treatment of Dementia (CCCDTD4) (163), American Psychiatric Association (APA) (154), World Health Organization (WHO) (162), Ministry of Health, Social Services and Equality & Galician Health Technology Assessment Agency (Availia-T) (173) and the Institute for Clinical Systems Improvement (ICSI) (161)
### Table 3. Domain Scores for AGREE II Evaluation

<table>
<thead>
<tr>
<th>Guideline (Year)</th>
<th>Domain 1 Scope &amp; Purpose</th>
<th>Domain 2 Stakeholder Involvement</th>
<th>Domain 3 Rigour of Development</th>
<th>Domain 4 Clarity of Presentation</th>
<th>Domain 5 Applicability</th>
<th>Domain 6 Editorial Independence</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Parkinson's Disease</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Zesiewicz et al. (2010)</td>
<td>56.9</td>
<td>29.2</td>
<td>64.6</td>
<td>72.2</td>
<td>17.7</td>
<td>79.2</td>
</tr>
<tr>
<td>SIGN (2010)&lt;sup&gt;1&lt;/sup&gt;</td>
<td>80.6</td>
<td>80.6</td>
<td>72.9</td>
<td>91.7</td>
<td>72.9</td>
<td>22.9</td>
</tr>
<tr>
<td>Grimes et al. (2012)&lt;sup&gt;3&lt;/sup&gt;</td>
<td>70.8</td>
<td>95.8</td>
<td>90.6</td>
<td>87.5</td>
<td>60.4</td>
<td>58.3</td>
</tr>
<tr>
<td>Berardelli et al. (2013)</td>
<td>72.2</td>
<td>19.4</td>
<td>47.9</td>
<td>86.1</td>
<td>12.5</td>
<td>6.3</td>
</tr>
<tr>
<td>Ferreira et al. (2013)</td>
<td>47.2</td>
<td>15.3</td>
<td>43.2</td>
<td>66.7</td>
<td>6.25</td>
<td>20.8</td>
</tr>
<tr>
<td><strong>Dementia</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>NICE (2011)&lt;sup&gt;2&lt;/sup&gt;</td>
<td>83.3</td>
<td>81.9</td>
<td>86.5</td>
<td>87.5</td>
<td>64.6</td>
<td>47.9</td>
</tr>
<tr>
<td>Hort et al. (2010)</td>
<td>58.3</td>
<td>38.9</td>
<td>54.2</td>
<td>66.7</td>
<td>25.0</td>
<td>62.5</td>
</tr>
<tr>
<td>AQuAs (2010)</td>
<td>87.5</td>
<td>69.4</td>
<td>73.4</td>
<td>84.7</td>
<td>57.3</td>
<td>79.2</td>
</tr>
<tr>
<td>Ihl et al. (2011)</td>
<td>68.1</td>
<td>38.9</td>
<td>57.8</td>
<td>48.6</td>
<td>19.8</td>
<td>64.6</td>
</tr>
<tr>
<td>CRCD (2011)</td>
<td>86.1</td>
<td>62.5</td>
<td>74.5</td>
<td>81.9</td>
<td>51.0</td>
<td>54.2</td>
</tr>
<tr>
<td>O'Brien et al (2011)</td>
<td>59.7</td>
<td>63.9</td>
<td>46.4</td>
<td>76.4</td>
<td>20.8</td>
<td>68.8</td>
</tr>
<tr>
<td>Sorbi et al. (2012)</td>
<td>68.1</td>
<td>38.9</td>
<td>53.7</td>
<td>65.3</td>
<td>26.0</td>
<td>62.5</td>
</tr>
<tr>
<td>Gauthier et al (2012)&lt;sup&gt;4&lt;/sup&gt;</td>
<td>73.6</td>
<td>70.8</td>
<td>70.8</td>
<td>87.5</td>
<td>50.0</td>
<td>79.2</td>
</tr>
<tr>
<td><strong>Mental Health</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Gelenberg et al. (2010)</td>
<td>68.1</td>
<td>41.7</td>
<td>61.5</td>
<td>66.7</td>
<td>32.3</td>
<td>60.4</td>
</tr>
<tr>
<td>Dua et al. (2011)</td>
<td>70.8</td>
<td>41.7</td>
<td>66.7</td>
<td>84.7</td>
<td>68.7</td>
<td>93.8</td>
</tr>
<tr>
<td>Avalia-T (2012)</td>
<td>88.9</td>
<td>70.8</td>
<td>79.2</td>
<td>75.0</td>
<td>49.0</td>
<td>60.4</td>
</tr>
<tr>
<td>Mitchell et al. (2013)</td>
<td>86.1</td>
<td>66.7</td>
<td>75.0</td>
<td>80.6</td>
<td>71.9</td>
<td>85.4</td>
</tr>
<tr>
<td><strong>Mean Domain Score (SD)</strong></td>
<td>72.1 (12.1)</td>
<td>54.5 (23.3)</td>
<td>65.8 (13.9)</td>
<td>77.0 (11.4)</td>
<td>41.5 (22.6)</td>
<td>59.2 (23.7)</td>
</tr>
</tbody>
</table>

1. Includes Grosset et al. 2010
3. Includes Patel et al. 2014
4. Includes Moore et al. 2014 (37), Herrman et al. 2013(168)

Standard Deviation (SD)
### Table 4. Statements & Recommendations for Parkinson's Disease

<table>
<thead>
<tr>
<th>Anxiety</th>
<th>Evidence for the Management &amp; Treatment of Anxiety in PD is Lacking.</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Level of Evidence</strong></td>
<td>AAN Level U (Uncertain or Lack of Evidence)</td>
</tr>
<tr>
<td><strong>Guidelines</strong></td>
<td>Zesiewicz et al. (2010), Grimes et al. (2012)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Depression</th>
<th>Screening for Depression in PD is recommended.</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Level of Evidence</strong></td>
<td>EFNS Level A (Effective), SIGN Level C (Case Control to Cohort Evidence)</td>
</tr>
<tr>
<td><strong>Guidelines</strong></td>
<td>Berardelli et al. (2013), Grosset et al. (2010)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Depression</th>
<th>There are several available tools screening for Depression in PD.</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Level of Evidence</strong></td>
<td>SIGN Level C &amp; Good Practice Point (GDS, BDI, HADS, MADRS &amp; HDRS) &amp; EFNS Class I (Diagnostic Accuracy Study)(MDS-UPDRS)</td>
</tr>
<tr>
<td><strong>Guidelines</strong></td>
<td>Grosset et al. (2010), Berardelli et al. (2013)</td>
</tr>
</tbody>
</table>

| Comment                                                                | A patient with PD should be screened for depression with either a clinician or self-rated tool. Diagnosis should not be based on the solely on the tool. Those with a positive screening test, should be referred for further assessment and diagnosis (including collateral history). |

| Practitioners should have a low threshold for diagnosing Depression in PD. | |
| **Level of Evidence**                                                  | CFNS Good Practice Point                                               |
| **Guidelines**                                                        | Grimes et al. (2012)                                                   |

| Treatment of Depression in PD needs to be individualized to each case. | |
| **Level of Evidence**                                                  | CFNS Good Practice Point                                               |
| **Guidelines**                                                        | Grimes et al. (2012)                                                   |

| Anti-depressant Therapy is recommended; there is little evidence to suggest one agent over another. | |
| **Guidelines**                                                        | Gelenberg et al. (2010), Grosset et al. (2010)                        |

| Tricyclic Antidepressants (e.g. Amitriptyline or Desipramine) have some evidence for treatment, but this must be balanced with the adverse effects (e.g. Anticholinergic). | |
| **Level of Evidence**                                                  | CFNS Level C (Possibly Effective)                                      |
| **Guidelines**                                                        | Grimes et al. (2012), Grosset et al. (2010), Gelenberg et al. (2010) |

| Selective Serotonin Reuptake Inhibitors have some evidence for treatment, but this must be balanced with the adverse effects (e.g. RLS, PLM, RBD). | |
| **Level of Evidence**                                                  | EFNS Class II (Prospective Matched Group Cohort or Controlled Trial) to Class IV (Uncontrolled Studies), APA Level II (Moderate Clinical Evidence) |
| **Guidelines**                                                        | Ferreira et al. (2013), Gelenberg et al. (2010)                       |

| Certain agents such as Amoxapine or Lithium should be avoided due to worsening of PD Symptoms. | |
| **Guidelines**                                                        | Gelenberg et al. (2010)                                               |
There is some evidence for the use of dopamine agonists (e.g. Pramipexole) & MAOI (e.g. Selegiline) for depression, but not for levodopa.

<table>
<thead>
<tr>
<th>Level of Evidence</th>
<th>EFNS Class I (RCT), Class III (Other Controlled Trial), APA Level I (Recommended with substantial confidence)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Guidelines</td>
<td>Ferreira et al. (2013), Gelenberg et al. (2010), Grimes et al. (2012)</td>
</tr>
</tbody>
</table>

There is insufficient evidence for the use of ECT, TCMS and psychotherapy in depression with PD.

| Guidelines        | Ferreira et al. (2013), Gelenberg et al. (2010), Grimes et al. (2012)                                    |
Table 5. Statements & Recommendations for Dementia

### Anxiety

**Patients with Dementia should be assessed for Anxiety (e.g. HADS).**

<table>
<thead>
<tr>
<th>Level of Evidence</th>
<th>AQuAS Level D (Expert Opinion)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Guidelines</td>
<td>AQuAs (2010), NICE (2011)</td>
</tr>
</tbody>
</table>

**Psychological Interventions can be considered for Anxiety in Dementia**

<table>
<thead>
<tr>
<th>Guidelines</th>
<th>NICE (2011)</th>
</tr>
</thead>
</table>

There is little evidence about the treatment of Anxiety in those with Dementia. Cholinesterase Inhibitors can be considered for treating Dementia-related behaviours, including anxiety.

<table>
<thead>
<tr>
<th>Level of Evidence</th>
<th>Level A (Meta-analysis or RCT)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Guidelines</td>
<td>AQuAs (2010)</td>
</tr>
</tbody>
</table>

### Depression

**Patients experiencing Dementia should be evaluated for Depression, including possible secondary causes.**

<table>
<thead>
<tr>
<th>Level of Evidence</th>
</tr>
</thead>
<tbody>
<tr>
<td>CRCD Level A (Useful), AQuAS Level D, WFSBP Grade 3 (Limited Evidence from Controlled Studies), EFNS GPP</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Guidelines</th>
</tr>
</thead>
</table>

**Patients with Depression in Dementia should be evaluated for suicide risk, however evidence varies.**

<table>
<thead>
<tr>
<th>Level of Evidence</th>
</tr>
</thead>
<tbody>
<tr>
<td>APA Level I (Substantial Clinical Confidence) or Inconclusive Gelenberg et al. (2010), Avalia-T (2012)</td>
</tr>
</tbody>
</table>

**Use of a valid screening tool (e.g. CSDD, GDS, HADS or DMAS) for Depression is recommended.**

<table>
<thead>
<tr>
<th>Level of Evidence</th>
</tr>
</thead>
<tbody>
<tr>
<td>AQuAs Level D to Good Practice Point, Low Quality Evidence, EFNS FPP/Class II (Prospective Study)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Guidelines</th>
</tr>
</thead>
</table>

**fMRI needs further study to determine its utility in Depression in the context of Dementia**

<table>
<thead>
<tr>
<th>Level of Evidence</th>
</tr>
</thead>
<tbody>
<tr>
<td>CCCDT4 Grade 2C (Moderate Recommendation, Low Level Evidence)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Guidelines</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gauthier et al. (2012)</td>
</tr>
</tbody>
</table>

**Therapy for Depression in Dementia should include a variety of Non-pharmacologic options.**

<table>
<thead>
<tr>
<th>Level of Evidence</th>
</tr>
</thead>
<tbody>
<tr>
<td>AQuAs Level C (Case-control, Cohort), APA Level II (Moderate Clinical Confidence)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Guidelines</th>
</tr>
</thead>
<tbody>
<tr>
<td>NICE (2011), AQuAs (2010), Gelenberg et al. (2010), Mitchell et al. (2013)</td>
</tr>
</tbody>
</table>

**Comment**

These include: cognitive behavioural therapy, reminiscence therapy, multi-sensory stimulation, animal-assisted therapy, exercise, stimulation-oriented treatment (recreational or pleasurable activities), or improvements to a living situation. Consider the involvement of carers.
Although evidence is mixed, a trial of Anti-depressants could be considered for Depression in Dementia.

**Level of Evidence**
- CCCDT4 Grade 2A (Moderate Recommendation, High Level Evidence), EFNS Class IV (Un-blinded, Expert Opinion), WFSBP Grade 5 (Inconsistent Results), APA Level II (Moderate Clinical Confidence)

**Guidelines**

When choosing an anti-depressant (E.g. SSRIs, SNRIs or TCAs) it is important to consider the anticholinergic side effects.

**Level of Evidence**
- EFNS Level B (Case-control, Cohort), EFNS Class IV (Un-blinded, Expert Opinion), APA Level I (Substantial Clinical Confidence) to APA Level II (Moderate Clinical Confidence), AQuAs Level B

**Guidelines**

**Comment**
- SSRIs (Citalopram or Sertraline) and TCAs have similar efficacy, but TCAs are not recommended given anticholinergic effects. SSRIs appear to be better tolerated. Other agents such as bupropion, venlafaxine and mirtazapine may be effective.

**Stimulants can be considered for treatment of Depression in Dementia.**

**Level of Evidence**
- APA Level III (Depends on Individual Circumstances), AQuAs Level B (Case-control, Cohort)

**Guidelines**
- Gelenberg et al. (2010), AQuAs (2010)

**Cholinesterase Inhibitors can be considered for treating Dementia-related behaviours, including depression.**

**Level of Evidence**
- Level A (Meta-analysis or RCT)

**Guidelines**
- AQuAs (2010)

**ECT can be considered in certain cases for Depression in those with Dementia.**

**Level of Evidence**
- APA Level II (Moderate Clinical Confidence)

**Guidelines**
- Gelenberg et al. (2010)

**Cholinesterase Inhibitors may improve neuropsychiatric symptoms in Lewy Body Disease**

**Level of Evidence**
- Level A (Meta-analysis or RCT)

**Guidelines**
### Table 6. Grey Literature Sources.

<table>
<thead>
<tr>
<th>Primary Topic</th>
<th>Websites &amp; Sources (n=83), Search Dates: July 24-Sept 6, 2015</th>
</tr>
</thead>
<tbody>
<tr>
<td>Disease Specific Websites for PD</td>
<td>Parkinson’s Society of Canada, Parkinson’s Clinical Guidelines, Pacific Parkinson’s Research Institute, Parkinson’s Disease Foundation, National Parkinson’s Foundation, Parkinson’s UK, American Parkinson Disease Association, Michael J Fox Foundation, Parkinson Alliance, Parkinson Action Network</td>
</tr>
<tr>
<td>Disease Specific Websites for Depression &amp; Anxiety</td>
<td>Depression Alliance, Canadian Mental Health Association, Mood Disorders Society of Canada, DepressionHurts.ca, Mental Health America, Anxiety and Depression Association of America, Anxiety UK, Anxiety Canada</td>
</tr>
<tr>
<td>Conference Proceedings</td>
<td>World Parkinson’s Congress, Canadian Neurological Sciences Federation Meeting, American Academy of Neurology Meeting, Movement Disorder</td>
</tr>
</tbody>
</table>
Box 2: Database Search Strategy

MEDLINE

Database: Ovid MEDLINE(R) In-Process & Other Non-Indexed Citations and Ovid MEDLINE(R) <1946 to Present>

Search Strategy:

1  "guideline*".ab,kw,ti. (215252)
2  "quality*".ab,kw,ti. (629529)
3  "standard* of care".ab,kw,ti. (26227)
4  "best clinical practice*".ab,kw,ti. (260)
5  "appropriate* of care".ab,kw,ti. (5038)
6  "RAND appropriate* method*".ab,kw,ti. (60)
7  "practice parameter*".ab,kw,ti. (933)
8  "performance improve*".ab,kw,ti. (4857)
9  "evidence based recommendation*".ab,kw,ti. (2513)
10 "performance indicator*".ab,kw,ti. (2173)
11 "guideline* for care".ab,kw,ti. (900)
12 "care pathway*".ab,kw,ti. (1984)
13 "position paper*".ab,kw,ti. (2386)
14 "position statement*".ab,kw,ti. (2589)
15 "health technology assessment*".ab,kw,ti. (2605)
16 Practice Guideline/ or Guideline/ or Guideline Adherence/ (49701)
17 Evidence-Based Medicine/ (58467)
18 Health Planning Guidelines/ (3946)
19 patient care management/ or comprehensive health care/ or critical pathways/ or "delivery of health care"/ or disease management/ or patient-centered care/ or physician's practice patterns/ (149817)
20 "quality of health care"/ or guideline adherence/ or quality assurance, health care/ or quality improvement/ or quality indicators, health care/ (144606)
21 1 or 2 or 3 or 4 or 5 or 6 or 7 or 8 or 9 or 10 or 11 or 12 or 13 or 14 or 15 or 16 or 17 or 18 or 19 or 20 (1086304)
22 "anxious*".ab,kw,ti. (12354)
23 "anxiety*".ab,kw,ti. (126885)
24 Anxiety/ (57207)
25 Anxiety Disorders/ (24675)
26 22 or 23 or 24 or 25 (155679)
27 "depressive*".ab,kw,ti. (79546)
28 depressed.ab,kw,ti. (82203)
29 "depression*".ab,kw,ti. (243896)
30 "mood disorder*".ab,kw,ti. (12207)
31 Depression/ (83554)
32 depressive disorder/ or depressive disorder, major/ or depressive disorder, treatment-resistant/ (81018)
33 27 or 28 or 29 or 30 or 31 or 32 (365749)
34 "parkinson*".ab,kw,ti. (83495)
35 "dementia*".ab,kw,ti. (75175)
36 "alzheimer*".ab,kw,ti. (102055)
37 "frontotemporal*".ab,kw,ti. (7403)
38 "lewy bod*".ab,kw,ti. (6601)
39 "huntington*".ab,kw,ti. (13638)
40 "primary progressive aphasia*".ab,kw,ti. (688)
41 "creutzfeld-jakob*".ab,kw,ti. (164)
42 dementia/ or alzheimer disease/ or aphasia, primary progressive/ or creutzfeldt-jakob syndrome/ or dementia, vascular/ or frontotemporal lobar degeneration/ or
PsycINFO
Database: PsycINFO <1806 to July Week 3 2015>

Search Strategy:

1  "guideline*".ab,kw,ti. (44333)
2  "quality*".ab,kw,ti. (163685)
3  "standard* of care".ab,kw,ti. (3609)
4  "best clinical practice*".ab,kw,ti. (94)
5  "appropriate* of care".ab,kw,ti. (1322)
6  "RAND appropriate* method*".ab,kw,ti. (3)
7  "practice parameter*".ab,kw,ti. (279)
8  "performance improve*".ab,kw,ti. (2751)
9  "evidence based recommendation*".ab,kw,ti. (381)
10  "performance indicator*".ab,kw,ti. (945)
11  "guideline* for care".ab,kw,ti. (169)
12  "care pathway*".ab,kw,ti. (435)
13  "position paper*".ab,kw,ti. (666)
14  "position statement*".ab,kw,ti. (510)
15  "health technology assessment*".ab,kw,ti. (213)
16  "anxious*".ab,kw,ti. (17072)
17  "anxiet*".ab,kw,ti. (147755)
18  "depressive*".ab,kw,ti. (79329)
19  depressed.ab,kw,ti. (40877)
20  "depression*".ab,kw,ti. (184377)
21  "mood disorder*".ab,kw,ti. (11680)
22  "parkinson*".ab,kw,ti. (24034)
23  "dementia*".ab,kw,ti. (47404)
24  "alzheimer*".ab,kw,ti. (43805)
25  "frontotemporal*".ab,kw,ti. (3959)
26  "lewy bod*".ab,kw,ti. (2674)
27  "huntington*".ab,kw,ti. (3709)
28  "primary progressive aphasia*".ab,kw,ti. (526)
29  "creutzfeld-jakob*".ab,kw,ti. (22)
30  1 or 2 or 3 or 4 or 5 or 6 or 7 or 8 or 9 or 10 or 11 or 12 or 13 or 14 or 15 (211714)
31  Treatment Guidelines/ (4907)
32  clinical practice/ (13977)
33  Evidence Based Practice/ (12366)
34  "Quality of Care"/ (9798)
35  30 or 31 or 32 or 33 or 34 (235115)
36  22 or 23 or 24 or 25 or 26 or 27 or 28 or 29 (94811)
37  Parkinson's Disease/ (15986)
38  Dementia/ (26011)
39  Alzheimer's Disease/ (35025)
40  Dementia with Lewy Bodies/ (1311)
41  Semantic Dementia/ (1141)
42  Parkinsonism/ (2478)
43  Presenile Dementia/ (276)
44  Picks Disease/ (256)
45  Vascular Dementia/ (1849)
46  37 or 38 or 39 or 40 or 41 or 42 or 43 or 44 or 45 (71696)
47  Creutzfeldt Jakob Syndrome/ (602)
48  36 or 46 or 47 (97137)
49  Major Depression/ or Atypical Depression/ or Treatment Resistant Depression/ or "Depression (Emotion)"/ or Recurrent Depression/ (117785)
50  18 or 19 or 20 or 21 or 49 (237253)
51  Generalized Anxiety Disorder/ or Anxiety Disorders/ or Anxiety/ or Anxiety Management/ (62827)
52  16 or 17 or 51 (159837)
53  50 or 52 (335914)
54  Huntington's Disease/ (2483)
55  48 or 54 (97161)
EMBASE
Database: Embase <1980 to 2015 Week 29>
Search Strategy:

---
1 "guideline*".ab,kw,ti. (317904)
2 "quality*".ab,kw,ti. (852308)
3 "standard* of care".ab,kw,ti. (41608)
4 "best clinical practice*".ab,kw,ti. (390)
5 "appropriate* of care".ab,kw,ti. (6584)
6 "RAND appropriate* method*".ab,kw,ti. (107)
7 "practice parameter*".ab,kw,ti. (1257)
8 "performance improve*".ab,kw,ti. (5963)
9 "evidence based recommendation*".ab,kw,ti. (3377)
10 "performance indicator*".ab,kw,ti. (3035)
11 "guideline* for care".ab,kw,ti. (1239)
12 "care pathway*".ab,kw,ti. (3652)
13 "position paper*".ab,kw,ti. (2814)
14 "position statement*".ab,kw,ti. (3087)
15 "health technology assessment*".ab,kw,ti. (3450)
16 "anxious*".ab,kw,ti. (16375)
17 "anxiet*".ab,kw,ti. (173966)
18 Anxiety/ (130802)
19 Anxiety Disorders/ (39045)
20 "depressive*".ab,kw,ti. (103664)
21 depressed.ab,kw,ti. (91013)
22 "depression*".ab,kw,ti. (316883)
23 "mood disorder*".ab,kw,ti. (18761)
24 "parkinson*".ab,kw,ti. (111067)
25 "dementia*".ab,kw,ti. (105709)
26 "alzheimer*".ab,kw,ti. (135974)
27 "frontotemporal*".ab,kw,ti. (10625)
28 "lewy bod*".ab,kw,ti. (9141)
29 "huntington*".ab,kw,ti. (16759)
30 "primary progressive aphasia*".ab,kw,ti. (1143)
31 "creutzfeld-jakob*".ab,kw,ti. (259)
32 Parkinson disease/ (104178)
---
33 parkinsonism/ (19901)
34 Pick presenile dementia/ or frontal variant frontotemporal dementia/ or senile dementia/ or multifarct dementia/ or semantic dementia/ or presenile dementia/ or dementia/ or frontotemporal dementia/ (99336)
35 CADASIL/ (1447)
36 Alzheimer disease/ (136199)
37 Creutzfeldt Jakob disease/ (9099)
38 primary progressive aphasia/ (1084)
39 Lewy body/ (5621)
40 24 or 25 or 26 or 27 or 28 or 29 or 30 or 31 or 32 or 33 or 34 or 35 or 36 or 37 or 38 or 39 (372226)
41 anxiety neurosis/ or "mixed anxiety and depression"/ or generalized anxiety disorder/ (15351)
42 16 or 17 or 18 or 19 or 41 (234712)
43 depression assessment/ or late life depression/ or treatment resistant depression/ or organic depression/ or depression/ or endogenous depression/ or long term depression/ or atypical depression/ or agitated depression/ or masked depression/ or reactive depression/ or major depression/ (298773)
44 20 or 21 or 22 or 23 or 43 (503331)
45 practice guideline/ (258652)
46 clinical pathway/ (6594)
47 standard/ (341430)
48 clinical protocol/ (72395)
49 professional standard/ (30377)
50 evidence based practice/ or evidence based medicine/ (123150)
51 quality control/ or health care quality/ (316946)
52 1 or 2 or 3 or 4 or 5 or 6 or 7 or 8 or 9 or 10 or 11 or 12 or 13 or 14 or 15 or 45 or 46 or 47 or 48 or 49 or 50 or 51 (1832439)
53 42 or 44 (623380)
54 40 and 53 (37476)
55 52 and 54 (5642)
56 limit 55 to yr="2009 -Current" (3617)
1. Grading of Recommendations Assessment, Development and Evaluation (GRADE)

**Figure 6: Different Evidence Grading Schemes Across Guideline**

<table>
<thead>
<tr>
<th>Author (Year) &amp; Organization of Included Guidelines</th>
<th>Evidence Levels &amp; Grading Schemes Used</th>
</tr>
</thead>
<tbody>
<tr>
<td>Zesiewicz et al. (2010) AAN</td>
<td>AAN</td>
</tr>
<tr>
<td>No Author (2010) SIGN</td>
<td>NICE</td>
</tr>
<tr>
<td>Grimes et al. (2012) CNFS &amp; PSC</td>
<td>EFNS</td>
</tr>
<tr>
<td>Berardelli et al. (2013) EFNS-MDS-ES</td>
<td>GRADE</td>
</tr>
<tr>
<td>Ferreira et al. (2013) EFNS-MDS-ES</td>
<td>SIGN</td>
</tr>
<tr>
<td>Hort et al. (2010) EFNS</td>
<td>Other</td>
</tr>
<tr>
<td>No Author (2010) AQuAs</td>
<td></td>
</tr>
<tr>
<td>No Author (2011) NICE</td>
<td></td>
</tr>
<tr>
<td>Ihl et al. (2011) WFSBP</td>
<td></td>
</tr>
<tr>
<td>No Author (2011) CRCD</td>
<td></td>
</tr>
<tr>
<td>O’Brien et al. (2011) BPA</td>
<td></td>
</tr>
<tr>
<td>Sorbi et al. (2012) EFNS</td>
<td></td>
</tr>
<tr>
<td>Gauthier et al. (2012) CCCDTD4</td>
<td></td>
</tr>
<tr>
<td>Gelenberg et al. (2010) APA</td>
<td></td>
</tr>
<tr>
<td>Dua et al. (2011) WHO</td>
<td></td>
</tr>
<tr>
<td>No Author (2012) Availia-T</td>
<td></td>
</tr>
<tr>
<td>Mitchell et al. (2013) ICSI</td>
<td></td>
</tr>
<tr>
<td>AGREE II Question</td>
<td>Mean Rating</td>
</tr>
<tr>
<td>------------------</td>
<td>-------------</td>
</tr>
<tr>
<td><strong>Domain 1 - Scope and Purpose</strong></td>
<td></td>
</tr>
<tr>
<td>Q1 - The overall objective(s) of the guideline is (are) specifically described.</td>
<td>5.88</td>
</tr>
<tr>
<td>Q2 - The health question(s) covered by the guideline is (are) specifically described.</td>
<td>5.24</td>
</tr>
<tr>
<td>Q3 - The population (patients, public, etc.) to whom the guideline is meant to apply</td>
<td>4.96</td>
</tr>
<tr>
<td><strong>Domain 2 - Stakeholder Involvement</strong></td>
<td></td>
</tr>
<tr>
<td>Q4 - The guideline development group includes individuals from all relevant professional groups.</td>
<td>4.83</td>
</tr>
<tr>
<td>Q5 - The views and preferences of the target population (patients, public, etc.) have been sought.</td>
<td>3.25</td>
</tr>
<tr>
<td>Q6 - The target users of the guideline are clearly defined.</td>
<td>4.72</td>
</tr>
<tr>
<td><strong>Domain 3 - Rigour of Development</strong></td>
<td></td>
</tr>
<tr>
<td>Q7 - Systematic methods were used to search for evidence.</td>
<td>5.59</td>
</tr>
<tr>
<td>Q8 - The criteria for selecting the evidence are clearly described.</td>
<td>5.10</td>
</tr>
<tr>
<td>Q9 - The strengths and limitations of the body of evidence are clearly described.</td>
<td>5.34</td>
</tr>
<tr>
<td>Q10 - The methods for formulating the recommendations are clearly described.</td>
<td>4.93</td>
</tr>
<tr>
<td>Q11 - The health benefits, side effects, and risks have been considered in formulating the recommendations.</td>
<td>5.41</td>
</tr>
<tr>
<td>Q12 - There is an explicit link between the recommendations and the supporting evidence.</td>
<td>5.78</td>
</tr>
<tr>
<td>Q13 - The guideline has been externally reviewed by experts prior to its publication.</td>
<td>4.28</td>
</tr>
<tr>
<td>Q14 - A procedure for updating the guideline is provided.</td>
<td>3.16</td>
</tr>
<tr>
<td><strong>Domain 4 - Clarity of Presentation</strong></td>
<td></td>
</tr>
<tr>
<td>Q15 - The recommendations are specific and unambiguous.</td>
<td>5.50</td>
</tr>
<tr>
<td>Q16 - The different options for management of the condition or health issue are clearly presented.</td>
<td>5.63</td>
</tr>
<tr>
<td>Q17 - Key recommendations are easily identifiable</td>
<td>5.74</td>
</tr>
<tr>
<td><strong>Domain 5 - Applicability</strong></td>
<td></td>
</tr>
<tr>
<td>Q18 - The guideline describes facilitators and barriers to its application.</td>
<td>3.44</td>
</tr>
<tr>
<td>Q19 - The guideline provides advice and/or tools on how the recommendations can be put into practice.</td>
<td>3.72</td>
</tr>
<tr>
<td>Q20 - The potential resource implications of applying the recommendations have been considered.</td>
<td>3.37</td>
</tr>
<tr>
<td>Q21 - The guideline presents monitoring and/or auditing criteria.</td>
<td>3.50</td>
</tr>
<tr>
<td><strong>Domain 6 - Editorial Independence</strong></td>
<td></td>
</tr>
<tr>
<td>Q22 - The views of the funding body have not influenced the content of the guideline.</td>
<td>4.53</td>
</tr>
<tr>
<td>Q23 - Competing interests of guideline development group members have been recorded and addressed.</td>
<td>4.57</td>
</tr>
</tbody>
</table>
CHAPTER 3: Barriers and Facilitators to the Use of Guidelines for Depression and Anxiety in Parkinson’s Disease or Dementia: A Qualitative Study.

Zahra Goodarzi MD FRCPC\textsuperscript{1,2}, Heather Hanson PhD\textsuperscript{1,3}, Nathalie Jette MSc MD FRCPC\textsuperscript{1,4,5}, Scott Patten PhD MD FRCPC\textsuperscript{1,7,8}, Tamara Pringsheim MSc MD FRCPC\textsuperscript{1,4-8}, and Jayna Holroyd-Leduc\textsuperscript{1,2} MD FRCPC

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2 Department of Medicine, University of Calgary and Alberta Health Services
3 Seniors Health Strategic Clinical Network, Alberta Health Services
4 Department of Clinical Neurosciences, University of Calgary
5 Hotchkiss Brain Institute, and O’Brien Institute for Public Health, University of Calgary and Alberta Health Services
6 Department of Psychiatry and Pediatrics, University of Calgary and Alberta Health Services;
7 Department of Psychiatry, University of Calgary and Alberta Health Services
8 Mathison Centre for Mental Health Research and Education, University of Calgary

Key Words: Parkinson’s Disease, Dementia, Depression, Anxiety, Guidelines

PENDING SUBMISSION

3.1. Abstract

Background: Despite the availability of clinical practice guidelines for the management of depression or anxiety in dementia or Parkinson’s disease (PD), these comorbidities remain under-diagnosed and under-treated.

Objectives: Our primary objective was to understand the barriers and facilitators associated with the implementation of high quality CPGs for depression and anxiety in patients with dementia or PD.

Methods: Focus groups and interviews were conducted with participants experiencing PD, their caregivers and physicians involved in the care of persons with dementia or PD in Calgary, Alberta. The Theoretical Domains Framework and Behaviour Change Wheel were used to guide data collection and perform a framework analysis. Evidence from the available guidelines was compared to reported physician behaviours.
Results: A total of 33 physicians and 7 PD patients/caregivers participated. We were unable to recruit patients/caregivers with dementia. Data were divided into three categories based on the barriers and facilitators to the implementation of guideline recommendations for diagnosis, management and the use of the guidelines. An overarching theme was the lack of evidence for depression or anxiety disorders in dementia or PD. This was more prominent for anxiety versus depression. Other themes included the lack of consistency between guidelines, lack of clarity in the language used, lack of applicability to the practice population, and impractical or out of date recommendations. Patients noted difficulties with communication of symptoms and access to services.

Conclusions: Although there are available guidelines, physicians have difficulty with the implementation of certain recommendations due primarily to a lack of evidence.

3.2. Introduction

Depression and anxiety are among the most common comorbidities for those with Parkinson’s disease (PD) and dementia (12, 13, 17-22). Approximately 35% of those with PD experience clinically relevant depressive symptoms (16). The point prevalence of anxiety in PD is estimated at 31%, whereas anxiety symptoms occur in up to 75% of dementia patients (12, 48, 58). Depression in dementia has an odds ratio (OR) of 2.64 (95% CI 2.43-2.86) (60).

Comorbid mood disorders are associated with reduced adherence to treatment, poor quality of life, and physical and cognitive impairment (24-29). Despite this, depression and anxiety are under-diagnosed and under-treated in these populations, representing a significant evidence to practice gap (45, 87, 90, 104, 174, 175). For example, only 20% of patients with PD or 18% of dementia patients diagnosed with depression receive treatment (23, 176).

Clinical practice guidelines (CPGs) should enable better diagnosis and management, by enabling health care professionals to provide better care, therefore reducing burden and improving patient quality of life (38-40). Despite the availability of CPGs, they remain underused clinically. Emphasis has been placed on guideline implementation and understanding underutilization of CPGs in order to address these gaps (87).

Previous studies identified overall barriers to guideline use as lack of awareness, familiarity, agreement, self efficacy, outcome expectancy and ability to overcome practice inertia.
and external barriers (45). Identified barriers should be considered during the guideline development stage (45).

Theoretical frameworks that explore physician behaviour help researchers understand provider behaviours of providers and possible targets for change (125-127). Theoretical Domains Framework (TDF) represents a comprehensive behaviour framework, which was synthesized from over 100 existing theories to 14 domains each representing different aspects of behaviours (126, 127). The behaviour change wheel (BCW) was built on this to help facilitate the development of implementation tools (125-127). The BCW is comprised of three behaviour categories called the COM-B system: capability, opportunity, and motivation (125).

In a preceding systematic review, our group synthesized high quality CPGs for depression or anxiety in dementia or PD (177). This earlier systematic review provides a detailed understanding of the current evidence for the management of these patients and the quality of existing CPGs, but does not explain why there may be an evidence-to-practice gap.

Our primary objective was to understand the barriers and facilitators associated with the implementation of CPGs for depression or anxiety in patients with dementia and PD. This was achieved through the use of a rigorous framework (TDF & BCW) to explore behaviours associated with guideline use. Understanding guideline use for these patients can contribute to the development of an implementation strategy targeting improved care of depression or anxiety disorders as experienced by patients with PD and/or dementia.

3.3. Methods

Design & Ethics.

This was a qualitative focus group and interview study using the TDF to examine the understanding of CPG recommendations for depression or anxiety in dementia or PD and the barriers/facilitators to their use by knowledge/end-users (134). Local ethics approval was received through the Conjoint Health Research Ethics Board (CHREB-14-449). All participants and researchers signed informed consent and confidentiality agreements.

Participants, Setting & Context.

Participants were divided into specialty and disease-specific groups in order to understand barriers to care specific for each end-user group. The groups were as follows: family
practitioners, geriatricians, geriatric psychiatrists, cognitive neurology (including neurologists and psychiatrists), movement disorders (including neurologists and psychiatrists), participants with PD, dementia and their family caregivers. All participants spoke English and were able to consent.

Physicians were recruited through convenience and snowball sampling. The sampling frame included physicians from acute care sites, specialty and non-specialty clinics, assisted living and long-term care facilities in Calgary. Physicians were included if they had experience with at least one patient with PD or dementia and comorbid depression or anxiety. Physicians were contacted via email from existing department lists and local contacts.

Patients were recruited using a convenience sample across the movement disorder, cognitive and geriatric medicine specialty clinics. This was purposeful, to ensure the recruitment from clinics with high proportions of patients that have the primary neurologic disorders. This was achieved by the placement of posters in specialty clinics and contacting patients from prior studies who consented to being contacted for future study. Patients and caregivers were included if they had a self-reported diagnosis of PD or dementia and a concurrent mood disorder confirmed by a specialist. We aimed to recruit caregivers of persons with advanced disease to help ensure we capture potential barriers across the disease continuum.

Data Collection & Handling.

The interview guides (Appendix E & F) were aimed at understanding the perspectives of the knowledge/end-users surrounding the barriers and facilitators to the use of these CPGs and was also informed by the preceding systematic review (Table 2, Appendix C & D were provided to participants before hand) (177) and TDF (Appendix G). The initial guides were reviewed by all members of the research team and approved by the CHREB. A few minor improvements to the wording of questions were made after the initial focus groups in order to improve their clarity.

All groups were conducted by the facilitator (ZG), in conjunction with a co-facilitator (JHL or HH). Interviews were conducted by one facilitator (ZG). All information was audio recorded and transcribed verbatim, and the co-facilitator recorded field notes. These notes provided the context of the discussion and to serve to bracket researcher bias and expectations (142). At the end of each group the facilitator provided a brief summary to the group as a
concurrent member check (143). Following the focus groups the facilitator (ZG) documented de-briefing notes, which were reviewed by the co-facilitator (JHL or HH). All transcripts were anonymized and verified by ZG with the recordings and field notes. The data were analyzed using NVIVO software.

**Analysis.**

A framework approach was used, which is defined as a content analysis method that involves summarizing and classifying data within a thematic framework (135). A key component of this analysis was the comparative ability across cases and within cases (144) (Table 12).

This analysis utilized the stages of familiarization, identifying themes, indexing, charting, mapping and interpretation (144, 145). This process was completed by three researchers (ZG, HH, JHL). Familiarization and identification was completed by ZG, with JHL and HH performing validation coding on 20% of the first half of transcripts. Due to a high correlation among all researchers initial coding, no further validation coding was undertaken. Indexing according to the TDF, charting, mapping and interpretation was completed by ZG and verified by JHL and HH. The team reviewed and discussed the meaning and context of these codes and how they should be categorized (144, 145). Discrepancies were resolved by discussion (144, 145). All codes were included, even if they did not readily fit into the framework, to avoid exclusion of potentially relevant data or outliers (144). All codes were broken down into barrier or facilitator categories (144, 145). The reported practices of participants were compared to the guideline recommendations to understand how physician practices align with CPGs.

**3.4. Results**

**Participants**

A total of 5 focus groups and 5 interviews² were completed, including 40 participants (21 females). Interviews took place when participants were unable to attend focus groups. Focus groups were conducted with six different stakeholder groups: geriatricians (n=6 participants), cognitive neurology³ (n=8), family practitioners⁴ (n=6), geriatric psychiatrists (n=8) and PD patients/caregivers (n=7). We were unable to recruit any patients or caregivers who met the

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² One of the family practitioner participants missed the part of the focus group, and at their request we did an interview to complete the first half of the interview guide at a later date. This interview material was collapsed into the focus group quotes to ensure it was not identifying.

³ Including neurologists (n=5) and neuro/geriatric psychiatrists (n=3).

⁴ Including those with the care of the elderly designation.
eligibility criteria for dementia. Interviews occurred for members of the Movement Disorders clinics including psychiatrists and neurologists.

All participants were recruited from Calgary. Calgary is a city of over 1 million (178), and the clinics are regional referral centers for Southern Alberta. Our Canadian health care system is a blend of insured and non-insured services for patients, where physicians are either salaried or on fee for service. Physicians work in an urban environment across four acute care sites, outpatient clinics, assisted living and long-term care institutions. Experience among the physicians varied from junior (< 1 year) to experienced (>30 years), both as consultants and attending physicians.

All participants in the PD group were recruited from the Movement Disorders clinic. Ages ranged between 43-76, and they described having primarily depression.

*Barriers & Facilitators to the Use of Guidelines. (Table 8; Table 11; Table 12).*

The 24 extracted guideline recommendations for depression or anxiety in dementia or PD were compared to the reported clinical behaviours and participant views (Table 11). All physician groups noted awareness of some of the available CPGs, however some participants noted that they were unaware of the breadth of CPGs in this area (Knowledge)

Several physicians reported not using CPGs in this area for a variety of reasons (Beliefs about Consequences). Barriers to CPG use included a lack of evidence (Knowledge), lack of consistency between CPGs (Knowledge), disagreement with or clinically impractical recommendations (Knowledge, Beliefs about Consequences), and out of date CPGs (Environmental Context and Resources).

“I don’t follow a specific set of guidelines because of what seems to be a real paucity of data …” (Psychiatry-Participant 1 (P1))

“…And the problem is there’s multiple guidelines so if you have a classic problems in Canada where they put up guidelines, the AAN hasn’t put out a guideline for 10 even longer yet still their guidelines are a little bit I think are more accurate than the Canadian guidelines.” (Cognitive Neurology-P4)

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5 Words in paraentheses represents TDF Domain. All codes are associated with TDF domains as seen in Tables 8-10.
“…Sometimes they can suggest certain medications, that I have found clinically not to work. So you have to kind of tailor your experience based on that. And your own experience.” (Movement Disorders–P1)

“I know there is some evidence for TCAs I must say I do not go near TCAs ever. No TCAs for me!” (Movement Disorders –P2)

“P3: I was surprised how positively they talked about Ritalin back in 2010, I wasn’t sure the evidence was clear then.

P6: Especially in dementia patients… it can interfere often causing stimulation…

P1: I think it’s a bit strong for an outline guideline.” (Geriatrics)

“(Referring to conflicting guideline statements) Um the evidence is inconclusive regarding dementia in suicide risk, I’m actually surprised at that. Especially when coupled with the second statement when saying patients with depression should be evaluated for suicide risk with depression in dementia should be evaluated …” (Psychiatry –P1)

Some groups found that there was an unclear link between the evidence and the recommendations, and that the level of evidence impacts the utility of recommendations (Knowledge, Beliefs about Consequences). Some groups identified that the CPGs were often vague (Memory, Attention & Decision Processes) or did not directly apply to the their patient population (Beliefs about Consequences). This all speaks to difficulty with guideline implementation (Goals), which was explicitly noted by family practitioners and movement disorder neurologists.

“So they are not really studying our patients. And I think the guidelines are actually quite meaningless in a lot of our populations in nursing homes and in geriatrics generally. All we are doing is extrapolating data from studies ... And yet we are expected to use these guidelines as something meaningful. Yes, so do I practice evidence based medicine, guideline stuff, not a lot cause they are not looking at my patients.” (Geriatric Psychiatry –P1)

Given this, physicians often found themselves managing these comorbidities in PD and dementia patients using their clinical experience in view of the limited evidence (Memory, Attention & Decision Processes). Physicians made several suggestions to improve implementation, including the creation of decision support tools or clinical care pathways
Behavioural Regulation. Family practitioners and specialists noted that the specialty CPGs are not always easy for a generalist to use (Environmental Context and Resources).

“I actually went back and read through the PD guidelines and they’re so long, they’re so much information in there that on a day to day period of time it would be really tough to pull those out and work with them.” (Family Practitioners–P2)

There were factors that did facilitate guideline use such as local CPGs (Environmental Context and Resources), guideline summaries (Memory, Attention & Decision Processes) or certain guideline agencies being perceived to be more reliable (Beliefs about Consequences). Different physicians identified different uses for the CPGs, such as use for teaching, background information or to identify primary literature (Knowledge, Skills).

**Barriers & Facilitators to the Implementation of Guideline Recommendations for Diagnosis** *(Table 9; Table 11; Table 12).*

Physicians agreed that mood disorders warrant detection (Knowledge, Beliefs about Consequences), but described in some cases a lack of awareness of tools (Knowledge), and lack of available tools (Environmental Context and Resources). Some participants found tools helpful for screening, to quantify symptoms, follow patients over time or facilitate conversation (Beliefs about Capability). Despite this there were concerns about the limitations of tools by all physicians (Beliefs about Consequences).

“Well its good to have its good for structure and consistently more of an objective assessment. And also for potentially following the changes over time, by being able to repeat that objective assessment.” (Family Practitioners-P6)

“… I actually don’t find the tools terribly helpful. My screening is any mood concerns but I don’t routinely have everyone do a GDS$^{6}$ or a Cornell$^{7}$” (Geriatrician –P5)

Across the groups, psychiatrists were least likely to use the tools (Beliefs about Consequences). All physicians directly involved in the care of dementia patients had concerns

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$^{6}$ GDS refers to the Geriatric Depression Scale
$^{7}$ Cornell refers to the Cornell Scale for Depression in Dementia (CSDD)
about the effect of dementia and tool administrator on tool accuracy (Beliefs about Consequences) and diagnosis (Knowledge).

“P5: Depends on the screening tool, you know. Especially if there is concurrent dementia, its almost routine to do the GDS.

P1: Its invalid.

P5: Especially when they are cognitively impaired” (Geriatric Psychiatry)

Geriatricians and psychiatrists agreed that suicide should be assessed for, despite the recommendations being divergent. Physicians commonly rely on narrative history to screen and diagnose mood disorders over tools (Beliefs about Capabilities).

“P2: I’d agree with that, yeah, I screen and sort of just the family members and them and just leave it at that unless there’s concerns.

P3: Yeah, I use narrative history” (Geriatricians)

Culture was felt to impact the accuracy of the screening tools by family practitioners and geriatricians (Social Influences). Patients and movement disorder neurologists found that the discussions about mood were validating to patient symptoms. (Emotions)

All physicians felt that a comprehensive approach was warranted, including looking for secondary causes. This was facilitated by the involvement of family or caregivers (Knowledge, Skills, Social Influences), and the use of a comprehensive approach to assessment (Knowledge, Skills). Most found that familiarity with the patient and available follow up, and the use of observation would facilitate diagnosis (Beliefs about Consequences).

All groups had concerns about symptomatic overlap of mood disorders with dementia, PD or apathy (Knowledge, Memory, Attention & Decision Processes). All physicians identified the psychiatrists as the gold standard for the diagnosis of mood disorders (Skills, Beliefs about Capabilities). However, most discussed that non-psychiatrists with expertise could make the diagnosis (Skills). Skills with communication were also identified to be important (Skills).
“…Do I think everyone who has mood disorders needs to see a psychiatrists? No. But, are psychiatrists the best able to <diagnose>? Yes.” (Geriatrician–P5)

Physicians find that patients often minimize their symptoms and that this is possibly related to social stigma (Social Influences). Whereas patients describe having difficulty with expressing their symptoms (Emotion).

“I felt lost. It felt like nobody was able to reach it and neither was I. So I just wandered around in a fog and it just… was the way it was.” (Patient-P7)

Barriers & Facilitators to the Implementation of Guideline Recommendations for Treatment.
(Table 10; Table 11; Table 12)

The approaches and experiences with the management of mood disorders varied between the physician and the patient groups. However, physicians were in agreement with the recommendations for an individualized approach to depression in PD, that certain agents should be avoided and that anti-PD drugs were reasonable to treat depression.

The non-psychiatric physicians described that there were limitations to their practice competency and it was noted that the comfort with prescribing drugs was variable (Beliefs about Capabilities).

“As a neurologist…in a sense I’m not that comfortable in treating depression.”
(Cognitive Neurology-P4)

Physicians also reported limitations when cases became complex (Beliefs about Capabilities). Patient preference plays a key role in determining the treatment plan (Beliefs about Consequences), however patients find it difficult to advocate for themselves (Emotion, Beliefs about Consequences). Patients and physicians had concerns about communication difficulty between specialists and family practitioners (Social/Professional Role).

“Being ill and being assertive at the same time and I’m having to work on that because you can fall through the cracks if you’re not” (Patient-P3)

There were many described environmental and resource limitations when it came to treatment surrounding access to specialists, limited time during appointments, and limited
follow-up. Some described providing plans to the family practitioners for therapy to ensure continuity and communication with family practitioners (Social/Professional Role).

The non-pharmacologic therapies were perceived by physicians and patients as very effective and physicians believed they should precede medications (Beliefs about Consequences).

“No medicine has ever worked and so it’s just been a long history of failure in that sense until recently when I started seeing a counsellor. That seems to have helped quite a bit.” (Patient-P6)

“…The point is it’s a short list of biological treatment. The big money is the non-pharmacological stuff so its as it ties in to some of the you know if not CBT per se then any milieu therapy any day programs like <they> can attend physical activity” (Cognitive Neurology-P5)

Therapies discussed were primarily cognitive behavioural, group, pet, exercise, light, music and tactile therapy (Knowledge). Other services that facilitate management included the members of the allied care team (Knowledge, Environmental Context & Resources). For all patient groups decreasing social isolation was described as a simple yet effective intervention (Knowledge). Despite this there were several barriers including limited access or physical barriers to non-pharmacologic interventions (Environmental Context & Resources), or diminished efficacy with cognitive impairment (Knowledge, Beliefs about Consequences).

“Perfect world is you could access non-pharmacologic as easy as pharmacologic and it would be done quickly. You wouldn’t have these long lines …” (Geriatrician –P1)

The psychiatrists had experience with ECT and psychotherapy, and thought that it had been demonstrated to be clinically useful despite its uncertain recommendation in PD. Non-psychiatrists were not comfortable with ECT or stimulants in dementia.

Experts agreed that anti-depressants were often warranted, but had concerns about drug-disease interactions, drug efficacy and the low evidence for both PD and dementia. It was clear across all groups that it was important to balance the risk of pharmacologic therapy when creating a plan (Knowledge, Memory, Attention & Decision Processes).
“…Take some time unless there’s great urgency to treat. Far away from pharmaceuticals. Because pharmaceuticals don’t work that good and they have their problems.” (Geriatrician–P1).

“P3: I think biologically or even with the other things for these patients, you want to consider what other comorbidities they have, what other medications are they on and drug interactions are there side effects of things that you want to take advantage of or P1: or avoid” (Geriatric Psychiatry)

Physicians reported the use of SSRIs commonly as a first line agent for PD and dementia. All physicians disagreed with the recommendation for the use of TCAs and stated it was impractical due to adverse effects and represented older evidence. Cost represents a barrier to many of the above therapies, notably exercise (Environmental Context & Resources). The use of cholinesterase inhibitors for depression or anxiety in dementia was contentious.

3.5. Discussion

In order to understand this gap in care we examined the use of CPGs by local stakeholders, and explored the barriers, facilitators and behaviours associated with guideline implementation. By using the TDF we identified behaviours associated with these actions, which will inform future studies on guideline development and implementation in this area.

A major theme when examining these CPGs was the lack of quality evidence supporting practice. This was clear for all aspects of anxiety care both in dementia and in PD, where the recommendations from the systematic review were minimal (177). The majority of the discussion in the focus groups and interviews was focused on depression, with some practitioners noting they were uncomfortable with the management of anxiety. While there was more evidence available for depression, physicians still had concerns about the validity and quality of the evidence.

Although some were unaware of the CPGs, barriers for physicians included the lack of evidence, the lack of clarity as to how the evidence informed the recommendations, the level of evidence, and disagreement with clinically impractical recommendations. This represents a concern as content is one of two determinants of guideline implementation, as it represents a major feature encouraging guideline use surrounding validity (87). The lack of evidence provides a target to improve guideline use, as physicians described that they would use them if there was more evidence and they were more applicable to their patients.
Physicians agreed that pharmacologic therapy is often warranted; but there were several concerns about the limited supporting evidence, drug interactions, and side effects. It was important to physicians that up-to-date evidence was linked to recommendations. For example, all physicians felt the recommendation to use TCAs was out of date and impractical given the side effect profile in these populations (PD and dementia). Recommendations such as these make physicians less likely to use CPGs. Physicians found in some cases the link between the recommendation and the evidence was unclear, thus leading to further concerns around validity and usability. This lack of agreement and beliefs about consequences have been previously reported as barriers to guideline use (45). However, here the disagreement with recommendations is specific to out of date evidence or concerns about evidence applicability to a specific patient populations. CPGs need to be updated more regularly than most currently are, as evidence suggests 19% of the recommendations are out-of within three years (132).

Other barriers to CPG implementation include issues surrounding the formatting of CPGs, including convoluted language, vague or divergent statements, and cumbersome documents. Some favoured local adapted CPGs with clear actionable recommendations. These behaviours reflect many aspects of recent implementability frameworks in which adaptation and applicability to local context is key to use (87).

Physicians in all cases agreed mood disorders should be screened for but were unaware of tools for anxiety, and had concerns about the validity of the depression tools. Given this, physicians described the use of narrative history, non-validated screening questions or observation to pick up depression. This is consistent with prior research in the area where FPs screening dementia patients for depression preferred to use ‘general indicators’ instead of tools (90). A systematic review of 36 studies of non-psychiatrists identifying depression by interview or chart review found a sensitivity of 36.4% and a specificity of 83.7% when compared to a gold standard psychiatrist (179). This furthers the argument for using tools with high sensitivity for depression case finding in PD or dementia. Systematic reviews have identified tools for depression case finding in these populations with sensitivities over 80% (66, 69).

Symptomatic overlap between the different types of depressive illnesses or overlap with depression and apathy or the neurologic conditions were noted as key barriers to diagnosis. Additionally, physicians perceive that patients minimize symptoms due in part to social or cultural barriers. Stigma has long been recognized as a barrier to diagnosis and therapy.
continuation, although this evidence is largely from the general population (180). Conversely PD patients did not describe stigma, but described having a difficult time expressing their symptoms to doctors. This is a nuanced difference between the perceptions of physicians and patients with PD. Neuropsychological studies of PD patients with depression, demonstrate that there is impairment in memory, verbal fluency, auditory attention and concept formation (181). Given this profile it is possible that these features affect the person’s ability to communicate their symptoms. This further supports the need for physicians to actively seek information regarding these symptoms to ensure they are detected.

Physicians and patients were in agreement with the use of non-pharmacologic therapy first, with several noting profound clinical benefit. The guideline recommendations from the preceding systematic review identified for dementia that there was evidentiary support the use of non-pharmacologic interventions, whereas in PD the recommendation was uncertain. Both the movement disorder neurologists and PD patients discussed dramatic improvement with psychotherapy, in some cases more so than medications. With physicians being surprised that the recommendation for non-pharmacologic therapy in PD was uncertain. This is in part because of their clinical experience but also recent evidence such as a randomized controlled trial published after the included CPGs, which demonstrated CBT reduced depression, anxiety and improved quality of life among PD patients (73). This highlights that physician’s need for up to date evidence in CPGs. Other treatment barriers were more physical or environmental related to the access to specialists, availability and affordability of non-pharmacologic treatments. These represent context specific barriers that could vary by practice location but represent targets for interventions to improve guideline uptake.

Physicians noted that treatment decisions and modalities were dependent on patient choice. PD patients noted that their symptoms can prevent them from accessing care and that they have difficulty advocating for themselves. Given that physicians want to engage the patients in treatment decisions, understanding that patients often struggle to advocate for themselves is important, as measures could be taken to facilitate their engagement. The non-psychiatrist physicians had more beliefs about practice limitations, in part due to implicit differences in their roles, but also due to lack of clarity with in the evidence and CPGs.

Overall when it comes to the use of CPGs in general, barriers were focused on knowledge, memory, attention and decision processes and beliefs about consequences –this was
related to concerns about the evidence or content of CPGs and to a lesser degree guideline format. The main concerns for diagnosis were related to knowledge, psychological skills, beliefs about capabilities and consequences. Whereas for management the concerns were largely related to environmental context, resources and beliefs about capabilities.

This study is unique to other studies in this area, as it is not focused on one guideline but rather a synthesis of high quality CPGs. It also focuses on the recommendations related to mood disorders among those with PD or dementia. Other studies however have identified similar barriers. A national survey of neurologists examining barriers to CPGs in PD found a lack of time, trouble aligning CPGs with patient preferences, lack of relevance, and lack of awareness were the major barriers (115). When it comes to reasons for poor adherence they found that old CPGs, drug side effects, patient wishes and financial concerns were major barriers (116). Similar barriers were noted for use of dementia CPGs by FPs (123). Here we identify that a prominent barrier to providing care for those with PD or dementia and comorbid anxiety or depression surrounds lack of evidence, concerns about screening tool accuracy, symptomatic overlap of disorders, access to resources, risks and poor efficacy of pharmacotherapy and beliefs about limitations to practice.

3.6. Limitations
Given the difficulty recruiting dementia patients and their family caregivers for a focus group, we are unable to comment on their experiences with co-morbid mood disorders. Of those recruited to the PD patient group, none had diagnoses of anxiety, however they did endorse symptoms of anxiety.

It was only feasible to have one focus group per stakeholder category, due the size of our center. Although scope of this study was local, reviewing international CPGs and employing a rigorous behaviour framework increases the transferability of our results to other centers.

For pragmatic reasons we used individual interviews concurrently with focus groups (182). However, there were no differences in the guides or materials provided, and the overall type or breadth of information shared by interview participants did not differ from those in the focus groups.

3.7. Conclusions
Although there are available CPGs in this area, physicians have difficulty with the implementation of certain recommendations due to a lack of evidence. In addition to this, key barriers identified to the use of CPGs in this area include concerns about screening tool accuracy, symptomatic overlap of disorders, access to resources, risks and poor efficacy of pharmacotherapy and beliefs about limitations to practice.

3.8. Acknowledgements
The authors would like to thank the many participants of the study for their time, dedication and openness to the research project. We would also like to thank Monika Khoury-Dool (MK), Administrative Assistant, for her transcription of the interviews and focus groups.

3.9. Authors’ Roles
ZG and JHL completed and submitted the ethics application to the local CHREB on behalf of the authors. HH and JHL assisted in the focus groups by providing the field notes and reviewing debriefing. Transcription was completed by MK and ZG. All transcripts were reviewed word by word by ZG and compared to the recordings to ensure no errors. JHL and HH performed validity check of coding. JHL and HH reviewed all coding associated quotes. The TDF domains, barriers and facilitators were assigned and reviewed by ZG, JHL and HH. ZG, HH, SP, TP, NJ and JHL provided input and reviewed the proposal, protocol, analysis and manuscript. All authors had access to the data, reviewed and approved the final manuscript. ZG, JHL and HH had full access to the data in the study and take responsibility for the integrity of the data and accuracy of the data.
### 3.10. Figures & Tables

#### Table 8. Barriers & Facilitators to the Use of Guidelines: using the TDF & BCW Frameworks

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Table 9. Barriers & Facilitators to the Implementation of Guideline Recommendations for Diagnosis: using the TDF & BCW Frameworks

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<td>Symptom Overlap with Apathy, Dementia, or PD</td>
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<td>Need for a Physician with Expertise to make Diagnosis</td>
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<td>Non-Psychiatrists Can Diagnose Mood Disorders</td>
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<td>Approach to Suicide Risk Assessment</td>
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<td>Family &amp; Caregiver Involvement in Diagnosis or Management</td>
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<td>Heterogeneity in Practice</td>
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<td>Use of Narrative History Over a Tool</td>
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<td>Skills with Communication with Patient &amp; Family (e.g. Rapport)</td>
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<td>Comprehensive Approach to Diagnostic Assessment</td>
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<td>Use of Observation for Detection of Mood Disorders</td>
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<td>Psychiatrists are the Gold Standard</td>
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<td>Memory, Attention &amp; Decision Processes</td>
<td>Knowledge</td>
<td>Diagnostic Criteria for Mood in Dementia &amp; PD Vary</td>
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<td>Differentiating Adjustment or Grief from Mood Disorder</td>
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<td>Symptom Overlap with Apathy, Dementia, or PD</td>
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<td>Social</td>
<td>Social Influences</td>
<td>Family &amp; Caregiver Involvement in Diagnosis or Management</td>
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<td>Patients Minimize Symptoms</td>
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<td>Culture Affects Tool Utility</td>
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<td>Social Stigma</td>
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<td>Physical</td>
<td>Environmental Context &amp; Resources</td>
<td>Reliability &amp; Availability of Collateral History</td>
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<td>Lack of Tools to Address Anxiety</td>
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<td>Suicide Risk isn’t Assessed in all Tools</td>
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<td>Reflective</td>
<td>Beliefs About Capabilities</td>
<td>Tools Can Help Quantify Symptoms</td>
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<td>Tools Can Help when Following a Patient Over Time</td>
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<td>Tools Help Facilitate Conversation</td>
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<td>Psychiatrists are the Gold Standard</td>
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<td>Use of Narrative History Over a Tool</td>
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<td>Motivation</td>
<td>Beliefs About Consequences</td>
<td>Familiarity &amp; Follow-up with the Patient Facilitates Diagnosis</td>
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<td>Tools for Depression Can be Helpful</td>
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<td>Tools For Depression Have Limitations</td>
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<td>Administration of the Tool can Effect Utility</td>
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<td>Dementia Affects the Use Screening Tool</td>
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<td>Do Not Use Tools</td>
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<td>Automatic</td>
<td>Social or Professional Role &amp; Identity</td>
<td>Reliability &amp; Availability of Collateral History</td>
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<td>Conversation About Mood was Re-Affirming or Validating</td>
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<td>Caregiver Burden (Assessment)</td>
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<td>Patients Have Difficulty Expressing Their Symptoms</td>
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### Table 10. Barriers & Facilitators to the Implementation of Guideline Recommendations for Management: using the TDF & BCW Frameworks

<table>
<thead>
<tr>
<th>COM-B System</th>
<th>TDF</th>
<th>Codes</th>
<th>Barrier or Facilitator</th>
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<tbody>
<tr>
<td>Capability</td>
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<td>Psychological Knowledge</td>
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<tr>
<td>Skills (Psychological)</td>
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<tr>
<td>Memory &amp; Attention Processes</td>
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<td>Physical</td>
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<tr>
<td>Environmental/Context and Resources</td>
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<td>Motivation</td>
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<tr>
<td>Reflective</td>
<td>Beliefs About Abilities</td>
<td>Case Complexity Effects Need for Referral</td>
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<tr>
<td>Social or Professional Role &amp; Identity</td>
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<td>Facilitator</td>
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<tr>
<td>Automatic</td>
<td>Social or Professional Identity (Automatic)</td>
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<tr>
<td>Emotion</td>
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<td>Difficulty Advocating For Themselves</td>
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<td></td>
<td>Symptoms (e.g. Apathy) Can Prevent Access to Care</td>
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</tbody>
</table>

- Low Threshold to Treat
- Deprescribing As Treatment
- Cognitive Impairment Effects the Utility of Non-Pharmacological Therapies
- Decreasing Social Isolation As Treatment
- Use of a Therapist, Psychologist, CBT, Behaviour Mapping, Dementia Case Manager or Homecare
- Use of ECT, Education, Exercise, Group, Light, Music, Pet and Tactile Therapy
- Use of Physiotherapy, Social Work, Occupational and Recreational Therapy
- Choosing Pharmacologic Therapy Requires Balancing Risk and Context.
- Approach Therapy from Major Symptoms
- Need to Re-Evaluate Medications Over Time for Effect
- Use of a Cholesterol Inhibitor, Dopamine Agonists, Antidepressants, & Stimulants
- Psychiatrists are the Gold Standard
- Education of Caregivers as Treatment
- Need to Re-Evaluate Medications Over Time for Effect
- Choosing Pharmacologic Therapy Requires Balancing Risk and Context.
- Approach Therapy from Major Symptoms
- Severity of Symptoms Can Dictate Treatment Urgency
- Patients Availability & Time Can Prevent Use of Non-Pharm
- Prescribing a Medication Is Easier than Accessing Non-Pharm Care
- Referral To Access or Initiate Treatment
- Availability for Follow-Up Facilitates Management
- Limited Availability of Follow-up Prevents Access to Care or Ability to Prescribe
- Able to Access Care When Needed
- Availability of Time Can Limit Assessment For Practitioner
- Book or E-Based CBT Facilitates Access
- Cost Can Prevent Access to Care
- Limited Access in General to Non-Pharmacologic Management
- Limited Access to CBT, Psychology or Group Therapy
- Limited Access to Day Programming or Recreational Therapy
- Limited Access to Exercise Interventions
- Limited Access to Services When there Is a Concurrent Neurological Diagnosis
- Limited Access to Translators
- Limited Availability of Consulting Services
- Physical Barriers to Accessing Care
- Research Studies Provide Access to Care
- Social Workers Facilitate Managing Mood Disorders
- Time Does Not Restrict Assessment
- Wait Times Can Delay Access
- Clinic Staff do not have the Time to aid in Diagnosis or Management
- Beliefs About Practice Limitation
- Comfort With Pharmacologic Therapy, Varies.
- Psychiatrists are the Gold Standard
- Both
- Case Complexity Effects Need for Referral
- Patients Have Difficulty Advocating For Themselves
- Treatment Modality Varies Depending on Patient Preferences
- Cognitive Impairment Effects the Utility of Non-Pharmacological Therapies
- Non-Pharmacologic Therapies Are Very Effective & Come First
- Concerns about the Efficacy of Pharmaceuticals
- Communication Breakdown Between Providers
- Involvement of Pharmacist Facilitates Treatment
- Co-Managed Care Facilitates Access (Same clinic)
- GP Facilitates Diagnosis & Treatment; Due to Familiarity & Follow-up
- MDT Facilitates Diagnosis & Treatment
- Providing Instructions to GP for Treatment
- Difficulty Advocating For Themselves
- Symptoms (e.g. Apathy) Can Prevent Access to Care

Barrier or Facilitator
### Table 11. Guideline Recommendations and Comparison to Reported Practices.

<table>
<thead>
<tr>
<th>Evidence is Lacking for Anxiety &amp; Depression</th>
<th>Statements or Recommendations From the Guideline Systematic Review for PD &amp; Dementia</th>
<th>Reported Practice or Views</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Evidence for the Management &amp; Treatment of Anxiety in PD is Lacking.</td>
<td>Agreement that evidence is lacking for anxiety.</td>
<td></td>
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<tr>
<td>2. There is little evidence about the treatment of Anxiety in those with Dementia.</td>
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<tr>
<td>G-P1: &quot;Um, I think like many people I’m probably more familiar and comfortable in looking for depression; anxiety is sort of a newer issue&quot; PSY2 &quot;Anxiety tools are very limited&quot;</td>
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<tr>
<td>3. Screening for Depression in PD is recommended.</td>
<td>Overall agreement that depression is common and should be examined for, lack of certainty on how to implement screening or which tool to use. Some practitioners use narrative history over a tool. There was awareness of several tools, but lack of clarity as to which tool was the most accurate or valid.</td>
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<tr>
<td>4. There are several available tools screening for Depression in PD.</td>
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<tr>
<td>MD1: &quot;we used Beck depression inventory and the PHQ 9&quot; PD-P3 &quot;I have a 6 month review with my neurologist. The last time I was in there 2 months ago he gave me a 10 questions regarding depression and I want you answer...&quot; MD2: &quot;I find that based on the questions that I ask versus what the tools shows us I think that there are inconsistencies. Because I think sometimes people with PD will answer certain things that actually have more to do with their parkinsonism as opposed to their depression. Some of it is more screening for apathy as well I think…. I think in some ways, I think you have more false positives and false negatives...&quot;</td>
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<tr>
<td>5. Practitioners should have a low threshold for diagnosing Depression in PD.</td>
<td>For both PD and dementia it was thought that a low threshold for diagnosis of depression was acceptable.</td>
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<tr>
<td>FPSY-P3:&quot;P3-Certainly in the PD patient the MSE has to be interpreted differently cause they have the masked face, they are motor retarded already, they are talking softly and you know its, so you do have to consider each symptom and say is this depression, could this be from PD, I think on balance, depression is something we can treat and I might be more inclined to try and treat it if there is any suspicion even if I think some symptoms may be related to the PD.&quot;</td>
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6. Patients with Dementia should be assessed for Anxiety (e.g. HADS). Generally practitioners feel less familiar with anxiety, few anxiety tools were discussed.

CN-P4: "The other scale we use, I guess that’s inconsistent in our cog clinics I certainly use it down south but is it a GAD-7"

FP-P4: "I have used the Hamilton anxiety scale but… I think for the most part very few patients are cognitively able to respond to that"

7. Patients experiencing Dementia should be evaluated for Depression, including possible secondary causes. Clear agreement that a comprehensive evaluation, of the patient was required as part of the diagnostic process.

PSY1: "...pursue the rest of the symptoms assessing whether or not those are actually related to a depressive illness or whether they’re more consistent with what we’d see in that neurologic condition or could they be related to the medication side effects that they’ve been put on etc. so, your hear me say this a thousand times, nothing exists in a vacuum you know, everything really um there’s a lot of interaction between the two and so I think if we are just putting pegs in slots that fit for depression we wind up um being very inaccurate."

8. Patients with Depression in Dementia should be evaluated for suicide risk, however evidence varies. Despite the uncertainty of the recommendation, there was discussion that suicide should be evaluated in Dementia and PD given the risk of harm.

G:"P1: ...I asked too and you know sometimes that’s why turn downs to GDS but also in patients it’s a nice entry point with people kind of say yes to a certain one you can kind of explore in one of them, like when you know the question, do you feel worthless, right, then you start talking

P3: When you talk about burden, you can ask them you know, do you ever feel your family would be better off if you were not here and you use that as the link to make it seem more like a natural question

P2: It sort of depends on the situation. I don’t ask all the time but I also sort of ask about firearms in the house."

9. Use of a valid screening tool (e.g. CSDD, GDS or DMAS) for Depression is recommended. Overall agreement that depression screening should occur. There was a lack of consensus on which tools were valid, and the use of a tool over narrative history. Not all practitioners aware of recommended tools.
CN-P1: "... baseline assessment where I am seeing a patient, we would almost always apply the short version of the GDS as a screening tool, which I find helpful"
G-P1: "Yeah I think screening does not always mean it’s a good tool um, I do find the GDS sometimes helpful if I’m not sure and sometimes I think just watching people reaction to a particular statements and um, kind of leads to further conversation…"
FPSY-P1: "Well again I think the stuff about the screening tools and the depression one in dementia, they talk about the Cornell scale. All of these tools are only as good as the person doing them and the person providing the information. If they are caregiver based ones. I think there is huge bias involved..."

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<tr>
<td><strong>10.</strong> Treatment of Depression in PD needs to be individualized to each case.</td>
<td>For both PD and dementia it was discussed that an individualized approach was necessary for diagnosis and treatment.</td>
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<tr>
<td>MD2: &quot;Definitely establishing rapport, its always different when you are seeing someone for the first time you are just kind of getting to know them and who they are, but I think kind of getting to so using the communication skills. I think a lot of it for me is sort of finding out who is this person and like what makes them who they are and what kinds of activities do they enjoy doing...&quot;</td>
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<td><strong>11.</strong> Anti-depressant Therapy is recommended; there is little evidence to suggest one agent over another.</td>
<td>Practitioners agree here that often antidepressants are used, but there are concerns for efficacy, and adverse drug events.</td>
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<tr>
<td>MD3: &quot;I would rather they (the FP) pick something they would comfortable with and familiar with especially since the evidence for which one to pick is a bit low anyways. And also the evidence for the effectiveness of antidepressants in general being not exactly spectacular either.&quot;</td>
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<td><strong>12.</strong> Tricyclic Antidepressants (e.g. Amitriptyline or Desipramine) have some evidence for treatment, but this must be balanced with the adverse effects (e.g. Anticholinergic).</td>
<td>Practitioners had concerns over the recommendation to even consider TCAs in practice. With all stating they would avoid TCAs. This is largely due to the major concern for adverse drug effects in these patients.</td>
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<tr>
<td>MD2: &quot;I know there is some evidence for TCAs I must say I do not go near TCAs ever. No TCAs for me!&quot;</td>
<td>MD3: &quot;Well just you know TCAs and older people is a bad idea, doesn’t necessarily work out so well. So its not exactly practical.&quot;</td>
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</table>
13. Selective Serotonin Reuptake Inhibitors have some evidence for treatment, but this must be balanced with the adverse effects (e.g. RLS, PLM, RBD).

Most practitioners described comfort and use of SSRIs as a first line pharmacologic agent for depression.

PSY1: "... there were some that talked about specific medication trials, you know, small ones um but the problem is it you know you look at some of these and some of them are not medications that were even using that often so you know looking at something like Nortriptyline or Desipramine um you have to find a pretty old looking psychiatrist to um a pretty mature psychiatrist to find somebody’s who’s prescribing these medications um paroxetine again is also not one that were seeing a lot of use fluoxetine in some cases however in you know the more medically complex Norfluoxetine the active metabolite is a very potent inhibitor so its not clean in drug interaction so you’re seeing you know a lot of these drugs that run through trials and you wonder why did they even initiate a trial on something like this when there’s really not a lot of people in real life practice who are using it. Um, you know the study on bupropion was um was interesting and I think well intended unfortunately and I don’t I don’t see it in your notes here but um tolerability was one of the big problems with bupropion"

14. Certain agents such as Amoxapine or Lithium should be avoided due to worsening of PD Symptoms.

Agreement from practitioners that these should be avoided.

15. There is some evidence for the use of dopamine agonists (e.g. Pramipexole) & MAOI (e.g. Selegiline) for depression, but not for levodopa.

Practitioners agreed that the use of the anti-parkinsonian medications was an effective treatment for mood symptoms.

MD1: "Some evidence with dopamine agonists, I agree with that, that’s something we have found particularly with Mirapex. Yeah there is definitely a mild antidepressant effect which I don’t think is there with the other dopamine agonists”

PSY1: "one easy example there some data may support the use of a dopamine agonist as a potential anti-depressant effect in patient PD so before I initiate something and if I wondered if there is room for that, we’ll have a discussion."
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<th>16. There is insufficient evidence regarding the use of ECT, TCMS and psychotherapy in depression with PD.</th>
<th>Experts note that ECT has been demonstrated to be clinically effective, although not first line. All practitioners and patients advocated strongly for the use of psychotherapy, CBT, exercise and other Non-pharmacological therapies as first line therapy. It was emphasised that CBT especially was very effective - in some cases more so than pharmacologic therapy. However, access is limited to the non-pharmacologic therapies.</th>
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<tr>
<td>PD-P1: &quot;CBT has been like amazing for me.&quot;</td>
<td>PSY1: &quot;its actually quite remarkable because they’re able to and what they don’t have in here um which I think is one of the other important points of an ECT is that ECT can often than spare patients that you know polypharmacy because they don’t need to stay on a number of the anti-depressants than.&quot;</td>
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<td>MD2: &quot;I’m a big proponent of non-pharmacologic therapy as I have seen some amazing results in some patients.&quot;</td>
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<td>17. Cholinesterase Inhibitors can be considered for treating Dementia-related behaviours, including anxiety &amp; depression.</td>
<td>There was general uncertainty about this recommendation. With some concerns about adverse effects, the aim or quality of studies and level of evidence behind the recommendations.</td>
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<tr>
<td>PSY 1: &quot;. . . that’s a bit of a that you know looking in a risk benefit that’s a harder one to support in my mind especially given the risks of cholinesterase inhibitors um even for anxiety and depression, I mean the benefit being modest I’m surprised its level A 2…&quot;</td>
<td>FPSY-P1: &quot;P1: I think its nice to use cholinesterase inhibitors and they do have some anxiolytic effects and some antidepressant properties. We also have to remember they can have uh an adverse effect of causing anxiety and irritability. You know as the disease progresses and you know I think that often doesn’t get recognized, and we end up adding antidepressants or some other medications. When all we really needed to was to cut back the cholinesterase inhibitor. So they can treat and cause the problem.&quot;</td>
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<td>18. fMRI needs further study to determine its utility in Depression in the context of Dementia.</td>
<td>Practitioners were surprised at this recommendation, but given that it is focused on further research did not disagree.</td>
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<tr>
<td>19. Therapy for Depression in Dementia should include a variety of Non-pharmacologic options.</td>
<td>Consensus by participants that non-pharmacologic therapy was very effective should be first line, individualized, and easy to access. There were concerns raised about the utility of psychotherapy in severe dementia, with experts qualifying that the type of therapy has to change as the dementia progresses, but that it should still be an option.</td>
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<td>G-P2: “At first consider like, depends on how really severe it is I guess but um I’d probably first try to engage them in some sort of like community program whether that’s an adult day support program or like a day hospital or something like that cause it seems like just getting out and meeting people doing things just helps some if they’re in the milder stages of cognitive impairment or dementia I should say with those symptoms, yeah”</td>
<td>PSY2: “We often talk about medications, but that these are in the background the other interventions are more important I think this focus on non-pharmacologic therapies is important to patients because it gives them some control and they are very helpful.”</td>
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<tr>
<td>20. Although evidence is mixed, a trial of Anti-depressants could be considered for Depression in Dementia.</td>
<td>Overall, practitioners agreed the evidence was variable for antidepressants for depression in Dementia. However, all felt that clinically there was utility to the use of antidepressants.</td>
</tr>
<tr>
<td>CN: “P5 well the list of biological treatments that are available is, it’s a short list I mean you can either do you know your cholinesterase inhibitor or your SSRI you might get a; P3 but its SSRI trials have failed they are not evidenced based...; P8 right but you, I mean you try what you have access to...”</td>
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<tr>
<td>21. When choosing an anti-depressant (E.g. SSRIs, SNRIs or TCAs) it is important to consider the anticholinergic side effects.</td>
<td>Along with this often medications were chosen to target major symptoms, and with recognition of the potential adverse effects. Practitioners were not in favour of the use of TCAs in patients with dementia, given the risk of adverse events.</td>
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<td>CN-P3: “P3 but that’s another example of the problem just in the levels of evidence… citalopram um for a long time was the most used drug in geriatric depression and there is not a single positive trial for CPG um etc., right. And the best SSRI trials are for agents that we would never touch with a ten foot pole now… paroxetine because its anticholinergic and fluoxetine because its profound drug interaction so how can you how can you actually apply that evidence to the real world. It’s terrible, there’s no real disconnect between the guidelines and the reality.”</td>
<td>G-P6: “P6: I think its certainly being comfortable too with the potential medication options if you’re prescribing so again um you know obviously being very aware of what the potential benefits are but the adverse effects I guess are more so the case if you’re trying to choose a particular type of medication and trying to balance that out with the patients comorbidities.”</td>
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and other medications. That can often be a bit of a challenge when you kind of plugging medications into your software data base and seeing all the potential interactions that arise and try to make a decision as to which is the best option and having that discussion with the patients and family."

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<tr>
<td><strong>22.</strong> Stimulants can be considered for treatment of Depression in Dementia.</td>
<td>Psychiatrists felt comfortable with the use of stimulants; other practitioners were aware of their use but would defer to psychiatry.</td>
</tr>
<tr>
<td><strong>MD1:</strong></td>
<td>&quot;Stimulants, so sometimes the psychiatrists will use this but this is definitely an example of what I would say the psychiatrist is something to do with their expertise I wouldn’t even try this.&quot;</td>
</tr>
<tr>
<td><strong>23.</strong> ECT can be considered in certain cases for Depression in those with Dementia.</td>
<td>Psychiatrists, specifically the geriatric psychiatrists were comfortable with the use and clear benefit of ECT. Other practitioners would refer to access this service.</td>
</tr>
<tr>
<td><strong>G-P3:</strong></td>
<td>&quot;ECT as well, again maybe we are not handling patients that are that severely depressed um so I haven’t had that experience with patients having that experience. I’ve had a few families who’ve asked and I’ve sent them all to Geriatric Psychiatry because I don’t feel qualified to answer the question.&quot;</td>
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<tr>
<td><strong>FPSY:</strong></td>
<td>&quot;P1: Its still the gold standard. P3: Yup including in dementia patients, we have had positive response to it.&quot;</td>
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<tr>
<td><strong>24.</strong> Cholinesterase Inhibitors may improve neuropsychiatric symptoms in Lewy Body Disease</td>
<td>No Comments</td>
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Table 12. Focus Group and Interview Codes in a Matrix with TDF & COM-B

<table>
<thead>
<tr>
<th>COM-B System</th>
<th>TDF</th>
<th>Focus Groups&lt;sup&gt;1&lt;/sup&gt;</th>
<th>Interviews&lt;sup&gt;2&lt;/sup&gt;</th>
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</thead>
<tbody>
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<td>Awareness of Guidelines</td>
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<sup>1</sup> Number of Participants Per Focus Group. 2. Number of Interviews.
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<td>Social Influences</td>
<td>Physical Context and Resources</td>
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<td>Availability of Follow Up Facilities Management</td>
<td>Limited Access to CBT, Psychology or Group Therapy</td>
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<td>Limited Availability of Follow Up Prevents Access to Care or Ability to Prescribe</td>
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<td>Ability to Access Care When Needed</td>
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<td>Culture Affects Tool Utility</td>
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<td>Limited Access to Services When There is a Concurrent Neurological Diagnosis</td>
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<td>Clinic Staff do not have the Time to aid in Diagnosis or Management</td>
<td>Clinic Staff do not have the Time to aid in Diagnosis or Management</td>
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**Note:** The above table outlines various social and physical influences and opportunities that patients might face when seeking care or support, including availability of services, access to care, and the need for specialized guidelines and tools to aid in diagnosis or management.
CHAPTER 4: Synthesis & Discussion.


The high prevalence and burden of comorbid mental illness in dementia and PD calls attention to the importance of knowledge and implementation if care is to be improved for these patients. The initial synthesis and quality assessment of guidelines and recommendations for the management of depression or anxiety in PD or dementia was crucial to our understanding of this knowledge to action gap. By synthesizing the recommendations we can identify clear gaps in evidence which inform future research questions, but also areas of knowledge that are potentially ready to be translated into practice. From a methodological standpoint we also identified areas where there are gaps in guideline quality that necessitate further development and improvement.

4.1.1. Guideline Characteristics

Identified high quality guidelines stem from key worldwide organizations. Regions such as South America or Africa were minimally represented; many middle to low-income countries were generally represented in WHO guidelines (162). Recommendations varied between countries depending on income, making this an important distinction (162).

Many guidelines (n=11) attempted to address cross-cultural differences. In all cases, the focus was on the mental illness or neurologic disease; and not the intersection of the two. This is an important concept that could be attended to more clearly in guidelines, as there are cultural differences in the experiences of the cross-section of disorders. Recent evidence demonstrates the prevalence of late life depression varies across different cultures in low to middle income countries (183). For example, a study focused on screening depression in elderly in Norway and Brazil, found Brazil had a much higher prevalence (184). This is important as it demonstrates that using the same tool across different cultures may yield different results. Additionally, there are concerns about language use and cultural appropriateness of tools designed in English and applied elsewhere (185). There appears to be minimal research on cultural differences with depression or anxiety in the setting of neurologic disorders. It may be important to examine these differences further in future study – but also have mention of these difficulties in guidelines.

Guideline development group size and composition appear to vary. Most groups were composed of physicians across relevant specialties and subspecialties. Ideally, given the scope of
most guidelines the development groups should be multidisciplinary to ensure that all stakeholders can review the evidence and have their views are represented (92). This could include members of the allied health team, such as nursing, physiotherapy, social work, psychology, and occupational therapy. Most guidelines were funded through non-commercial means. Only two had partial pharmaceutical funding, and one did not state the source of funding.

Conflicts of interests for guideline development groups are listed, but in some cases it is not clear how these conflicts were managed. This resulted in a lower rating of Domain 6 in regards to editorial independence (mean score 59.2 (SD 23.7)). In the highest quality sections, procedures for managing conflict were well delineated. For example, experts with conflicts related to pharmaceuticals were excluded from discussion of the pharmaceutical content, but participated in development of other aspects of the guideline. It is important to address conflicts of interest by declaring them a priori, and outlining their review and management. Especially since some practitioners have concerns about the role of industry in guideline creation (123).

4.1.2. Guideline Quality

At the full text phase of the review, it became clear that the lowest quality scores were assigned to guidelines lacking a method sections. Despite multiple attempts to obtain details, further information was not sufficient to allow inclusion of any of the low quality guidelines. In many cases, information received consisted of partial methods, messages from administrators that requested information was not available, or no reply. There do not appear to be standards for the duration that information about guideline methods/data should be kept. Ideally, information should remain available for the period that the CPG are relevant. In some cases, changes in roles or lack of access to information made further data collection impossible.

Guidelines are often criticized for being cumbersome (45). It appears that some guidelines were shortened to recommendations with a brief rationale, perhaps to increase usability. To address this, organizations could publish a brief CPG document and methods separately. In some cases we were unable to access any further information on methods. Although the shortened version may be of use clinically, it had a poor rating from the perspective of quality. Clarity of methods used in guidelines, gives confidence to users that development was rigorous and that the resulting recommendations were well founded.
Nine guidelines were found in the databases and eight in the grey literature. Those from
the databases had quality scores ranging from 4 and 6.5, with a mean of 4.80 (SD 0.77). The
quality scores in the grey literature ranged from 4.75-6.5 with a mean of 5.56 (SD 0.56). This
demonstrates no improvement in guideline quality associated with journal publication that is
typically associated with a secondary editorial and peer review. Given the word limit of most
journals many of the published guidelines had smaller methods sections than those published on
guideline sites which could have effected the quality scores due lack of detailed methods.

There were 22 elements identified in a guideline implementability framework that suggest
several means to improve implementation (87). Early attention to implementation in the
guideline development process may aid in uptake downstream (87). Commonly, guidelines
employ summary tables and alternate versions, such as those from SIGN (165). In this instance,
the organization published the full guideline on their website and a summary in a scientific
journal (165). Gagliardi et al. suggest that summarized and tabulated information, alternate
versions, and individualized information specific to context increases success of guideline
implementation. Adaptation to individual context was only seen in the CCCDTD4 guidelines,
where a specific summary was published for family practice (37).

A large proportion of citations were excluded due to lack of relevance. There were two main
reasons for this. First, certain documents labelled as guidelines were not truly guidelines based
on the primary definition. Often these were best practice documents, narrative reviews,
textbooks, or opinion statements. This raises the issue of guideline indexing in the literature, and
how misuse of the term can lead to confusion (164). Secondly, several citations were excluded
because the guideline did not address the comorbid conditions. The inclusion of comorbidities as
part of a guideline is the main focus of this review. 40 identified guidelines did not account for
the relevant comorbidity in the full text review. The application of multiple guidelines to one
person can result in unreasonable treatment plans, making the discussion of comorbid illness in
guidelines particularly relevant to practitioners (186). A lack of evidence may contribute to
exclusion of comorbidities in many guidelines (93).

Using the AGREE II quality assessment ratings, the lowest rated domains were 2
(Stakeholder Involvement), 5 (Applicability) and 6 (Editorial Independence). The lowest rating
was in applicability, with an average score of 41.5 (SD 22.6). This section assesses whether the
guideline describes barriers and facilitators, discusses implementation, resource implications, or
monitoring/auditing criteria. These four questions were all rated below 4, on average, with high variance. Very few guidelines had separate sections addressing dissemination or implementation. In most cases, domain information was throughout the text.

Guideline implementation was examined in a 2015 systematic review of 20 studies, including 137 guidelines (95). They found that applicability scored lower than any other domain in the AGREE II (mean score 43.6, median 42.0) (95). This did not appear to change with year of publication, however the country/organization did have an effect (95). Guidelines, like any other form of evidence, need active implementation (93). Failure to do so results in poor uptake of recommendations, leading to variation and gaps in care (97). Carefully designed and tailored interventions can improve guideline uptake (97). It is key that implementation is considered as part of guideline development (97). Tools have been developed to assist in integrating implementation plans into the process of guideline creation (101). Further, other tools are available to assess existing guidelines and improve implementation (GUIDE-IT) (102). Given the recent nature of these guideline implementation tools they would not have been included as part of the development or assessment of included guidelines. In the future, these tools have the potential to improve guideline implementation.

Stakeholder involvement (Domain 2) was the second lowest rated domain, with a mean rating of 54.5 (SD 23.3). This was partly due to the lack of target population representation (Question 5; mean 3.25 (SD 1.92)). This process is described as ‘consumer involvement’ and is a key component of quality guidelines. The goal is to represent patient views, improve implementation or applicability, and ensure an open process (92, 187).

The lowest rated item overall was related to procedures for guideline updates (Question 14; mean 3.16 (SD 1.73)). Many guidelines state a timeline for review, or that the guideline will require review, but further details were lacking. In some cases, organization website review yielded information about guideline review status or projected review date. Evidence changes rapidly, up to date guidelines are necessary to accurately guide practitioners (132, 188). A recent survival analysis of guidelines demonstrated that most recommendations were out of date within 3 years (132). In order to maintain relevance from a clinical perspective, guidelines must have up to date reviews of evidence and frequent updates of recommendations.
4.1.3. Guideline Content

The content of guidelines was extracted verbatim and categorized based on major topics covered in the recommendations. Anxiety, as a comorbidity of dementia or PD, is poorly represented in recommendations due to a lack of evidence. Two major guideline organizations, the AAN and the CNSF, note this. There were no recommendations on the diagnosis or management of anxiety in PD. For dementia, there were two guidelines that supported assessment for anxiety; only one specifies a tool (Hospital Anxiety and Depression Scale (HADS)) (156). Although, there was no diagnostic accuracy evidence presented to support this. The NICE guidelines suggest assessment and management with non-pharmacologic therapies for anxiety; but, supporting discussion largely refers to depression (138). Evidence tables describe mainly quantitative data for depression (138). Interestingly when looking at their references one study by Spector et al. noted improvement in anxiety and depression with CBT targeted at anxiety (77, 189). For example they note statistically significant improvement on the primary outcome of changes in RAID scores (77, 189). Where other results favour CBT for anxiety but were not statistically significant (77, 189). These recommendations for anxiety were linked to their recommendation for depression in both guidelines. The included studies for this review rarely mentioned anxiety versus depression. Often, anxiety was mentioned as part of a list of symptoms. This paucity of evidence for anxiety in PD and dementia represents a major gap for the care of these patients.

Recommendations for depression were more frequent than anxiety, although levels of evidence and agreement vary across guidelines. For both PD and dementia, screening for depression was recommended. The levels of evidence for screening for depression in PD varied from a Good Practice Point to Class 1 Diagnostic Accuracy studies (153, 165). A range of tools, the BDI, GDS, MADRS, HDRS and UPDRS, are suggested. One guideline noted that these tools are important for screening, but are not diagnostic (165). In these guidelines there was no mention of the diagnostic accuracy information in the text (e.g. SN or SP) or the cut offs that should be used, however they are clearly referenced.

For dementia, there were more detailed recommendations for diagnosis than PD. These included ruling out secondary causes and evaluating suicide risk. The two guidelines that made recommendations about suicide risk were divergent. One stated a lack of evidence (159), and the second stated a Level 1 recommendation to evaluate (154). The recommendation to screen
precedes that which says evidence is lacking. It is possible that the two organizations had different views on the evidence and its role in these patients. For dementia patients, screening with a valid tool such as the CSDD, GDS, DMAS or HADS was recommended. Again, the evidence ranges from Good Practice Point to Class 2 prospective studies. One guideline did report the diagnostic accuracy information and included a cut-off (161).

Therapeutic recommendations for depression in PD and dementia were similar. Both recommended a trial of anti-depressant, but provided little evidence to guide the choice of therapy. Both cases noted evidence for the use of SSRIs or TCAs, and advocated for the balancing of risk of side effects.

There was evidence to support the use of non-pharmacologic therapies for depression in dementia with several examples listed. The evidence supporting these was Level II to Level C. It is important to consider a wide range of therapies in relation to changes in cognition over the course of illness. Interestingly, ‘insufficient evidence’ was reported for psychotherapy in PD patients with depression. This counters the evidence of RCTs demonstrating the effectiveness of CBT (72, 73). These studies both occurred after the searches of included recommendations, and highlight the importance of up-to-date evidence.

Overall, evidence for the treatment of depression in dementia and PD continues to be variable. Further high quality studies are recommended.

4.1.4. Limitations to the Systematic Review

Limitations to this study include a few issues common to systematic reviews. One of the main concerns is heterogeneity in terminology used within guidelines. Our search incorporated key words and indexed terms for all variants of the words used for guidelines across three databases in all languages. The search also employed depression or anxiety terms, and it is possible that this was restrictive. These terms were needed to ensure practicality of the search. Developing and reviewing the search strategy with experts and an experienced librarian addressed both of these concerns. This search was verified by a librarian external to the development process using the checklist from PRESS to validate and ensure accuracy of the search (131).

To ensure a comprehensive search we contacted content and methodological experts, searched references of included studies, and performed an extensive search of grey literature.
(n=83 sites). Two authors independently searched relevant sites. We were unable to search all languages for grey literature, but we used the Google translate function to search disease/organization relevant sites not published in English where possible. Searching the grey literature sites is often limited by the quality of the search engine inherent to the site. Our search strategy for the grey literature sites was to search by neurologic disease with comorbid mental health disorder using Boolean operators. If that was not successful, the search was broadened by using only the neurologic condition or the mental health disorders, and results were hand searched.

The search was limited to the past five years, however this was done purposefully given the concern about guideline evidenced being out of date at 3 years based on survival analysis (132). Inclusion of older guidelines, which do not include the more recent data, has the potential to produce conflicting recommendations.

The use of the AGREE II tool allows us to assess the global quality of guidelines. However, this does not provide a framework for detailed evaluation of the guideline search strategy or included evidence. Instead these items are rated globally in the AGREE II tool, and those guidelines of overall low quality were excluded. If it was clear on the initial assessment that a guideline was of low quality, but that this could be reconciled with more information –the primary guideline organization and authors were contacted. Any retrieved information was incorporated into the AGREE II assessment and scores were adjusted if needed. In many cases, additional requested information was either not available or there was no response despite multiple attempts. We are unable to directly compare extracted recommendations between guidelines due to heterogeneity in guideline evidence levels and grading schemes. On going research hopes to develop a tool, the AGREE-REX, to evaluate of the quality of the recommendations and evidence in guidelines (190).

There is some evidence to guide clinical practice for anxiety and depression in dementia and PD. This appears to vary in quality and strength according to the guidelines. Major gaps exist in the diagnosis and management of anxiety for PD and dementia. The identification of depression in PD and dementia has clear recommendations, although of varied evidence levels. Stronger, more conclusive evidence is needed for management of depression. In many cases, evidence for management appears to be lower quality, and there is little evidence to guide management decisions. In combination with gaps in literature, varied recommendations and levels of evidence
lead to clinical uncertainty and variance in practice. This synthesis of current guidelines identifies major gaps in guideline reporting and targets for further knowledge inquiry. A clear understanding of guidelines and evidence helps to prioritize evidence implementation in practice.

4.2. Assessing Determinants of Knowledge Use: Qualitative Study

Although guideline recommendations for the diagnosis and management of depression or anxiety in dementia or PD are available, there are gaps in the care of these patients. The first step in addressing these gaps requires an understanding of how local practice aligns with recent high quality recommendations. The second step was to explore the barriers, facilitators, and behaviours associated with guideline use and implementation. Understanding the behaviours that drive clinical decisions and activities is necessary to develop actionable and effective implementation strategies. Practices described by stakeholders generally agreed with guideline recommendations. A few notable exceptions surrounding screening and management of depression were observed.

4.2.1. Guideline Use

Content and format are the two key components of guideline implementation (87). The chief barrier to the use of these guidelines was the content or its lack of evidence. Similar to the guideline systematic review, participants identified a dearth of evidence or recommendations related to anxiety in dementia or PD. Practitioners felt more comfortable with depression, noting availability of more recommendations; but still vocalized concerns about the validity and quality of evidence.

Concerns focused on a lack of clarity about how the evidence informed recommendations, and disagreement with impractical or out of date recommendations. Some practitioners were unaware of the breadth of guidelines and recommendations available, which is possibly due to the scope of guidelines included. This represents an issue with awareness or access to guidelines –which is key for guideline uptake (87).

It was clear that expert end-users rarely used guidelines in practice because of these barriers. The concerns about evidence relate to the paucity of research available to guide diagnosis or management of anxiety in these disorders. This creates a difficult situation for practitioners trying to manage patient symptoms without clear guidance.
The level of evidence affects the utility of the recommendation. Lower level evidence is less useful clinically, and having no recommendation does nothing to aid practice. Focus group findings suggest that expert agreement in these situations would be better than no recommendation. This would provide a consensus for practitioners, and a potential target for evaluation. Rigorous techniques, such as the Delphi method or high quality guideline panels, enable experts to make group recommendations (191).

It was important to practitioners that up to date evidence be linked to recommendations. In the case of the TCA recommendation for depression, all practitioners felt this was an impractical and risky suggestion due to the side effect profile. However, other practitioners clarified that the evidence behind this recommendation was out of date. With TCAs there is clear evidence-demonstrating harm, with a higher number needed to harm for TCAs versus SSRIs in the general population and higher rates of withdrawal due to side effects (192, 193). Therefore, recommendations such as these make practitioners less likely to use guidelines as they are perceived to be less credible based on contrary evidence. In other cases, practitioners felt that the recommendation was not clearly linked to evidence. This was exemplified in the use of stimulants in dementia. Here, more clarity in the connection between the guideline recommendation and evidence is needed. Provision of clear evidence summaries and tables was recommended to overcome this (87).

There were also concerns about vague non-actionable statements and language used in guidelines. Use of qualifiers, such as the word ‘severe’ when discussing depression, leads to uncertainty with the use of the recommendation in the clinical setting. In this case, the guideline authors did not provide information on what was defined as severe or why that clarification was necessary. Vague recommendations hinder practitioners by not providing sufficient clinical direction or targeting behaviours (194). It was noted that there were also divergent recommendations, which lead to further confusion about the correct course of action.

Practitioners had concerns about the applicability of guidelines to their practice population. For example, the geriatric psychiatry group often practices in LTC where patients have complex comorbidities and often more severe disease. Most studies excluded these patients. When the evidence supporting recommendations is based on uncomplicated patients, practitioners experience difficulty in generalizing guidelines to their patients (93, 123). It is difficult to account for all comorbidities when addressing a primary condition in guidelines,
largely because the evidence base does not account for these (93). Work by the American Thoracic Society looked at this concern as it relates to Chronic Obstructive Pulmonary Disease (195). The recognition that managing comorbidities is a gap in guidelines is key going forward. They recommend that to address this CPG development committees should be multidisciplinary, should evaluate the evidence and recommendations as they apply to a multi-morbid population, and further research needs to be done to examine these patients with complex comorbidity (195). Immediate recommendations were that CPGs should at least address the common comorbidities in the setting of the primary disease and the impact they have on the condition clinically (195).

Facilitators of guideline use included provision of background and alignment to practice, but specialty guidelines were found to be cumbersome. Generalist practitioners favoured locally adapted guidelines with clear actionable recommendations. Similarly, junior practitioners used guidelines to provide references for primary literature and align practice.

These behaviours raised interesting concepts regarding the differences in guideline use by specialty practitioners, and practitioners with different experiences. It would seem reasonable that experts involved in the creation of guidelines would be more aware of evidence, and therefore less likely to use the guidelines. In some cases, these experts preferred primary literature to guidelines, to ensure their own awareness of the evidence. This is tied to the goal of providing evidence based care, informed by an independent review of evidence. However, this is not always practical or possible for more generalist practitioners (123).

Major domains identified from the TDF as barriers were that of beliefs about consequences, knowledge and memory, attention and decision processes. These were focused on participant concerns about the content of guidelines. Facilitators were the use of guidelines for other para-clinical activities, mainly through psychological skills. Guidelines were primarily used for teaching, background information, and identifying literature.

4.2.2. Guideline Implementation: Diagnosis

In all cases, practitioners agreed that depression or anxiety should be screened for, but were unaware of tools for use with anxiety. Practitioners were aware of more tools for depression, but had concerns about the utility and validity of the tools.

The detection of depression in dementia was a key behaviour identified by Murphy et al. in their study of dementia guidelines (90). In this study, three categories of behaviours are
described: physician use of validated tools, physician use of general indicators, and absence of physician assessment of depression. The participants in the current study all described some form of assessment, either use of a tool or assessment based on an initial history. Practitioners described the use of narrative history as a way to detect depression, especially as some perceive the tools to be of limited use or validity. This use of a narrative history to screen for depression has been examined in other studies as outlined above in Chapter 3. The use of narrative screening by non-psychiatrist practitioners has low sensitivity and is less effective for case finding (179) (196).

Screening tools for depression or anxiety are designed for use in the detection of disorders by varied clinical staff. The focus group responses revealed that psychiatrists rarely used tools, where as non-experts described their use. This relates to the identified role here of the psychiatrist as the ‘gold standard’ for diagnosis. Often, psychiatrists describe seeing patients who have had a positive screening tool completed by another practitioner. For non-psychiatric experts such as family doctors, neurologists, and geriatricians, they describe tool use as possibly aiding in identification of patients who warrant further assessment or referral. Typically, non-psychiatric assessments are multifaceted, and the use of case finding tools targets assessment to aid in diagnosis. This is not to say that non-psychiatrists cannot diagnose depression or anxiety but that typically their assessments, especially in this context are multi focal, so the use of case finding tools helps to target assessments. The participants in this study agree that the psychiatrists are gold standards, but non-psychiatrists can also diagnose depression or anxiety following experience in this area.

Several positive features of tools were also noted. These features included quantification of symptoms, conversation facilitation, and longitudinal follow up. The use of the tools to facilitate conversation is unique. Practitioners found that tools promoted conversation about mood and suicidality. This enabled practitioners to incorporate somewhat difficult topics into conversation easily and obtain more detailed histories. Of note only some tools are sensitive to change with time and medications, such as the CSDD (197).

Culture, cognitive impairment, and the experience level of the tool administrator were suspected by participants as affecting the psychometric properties of tools. Cultural differences are known to affect epidemiology and detection of depression (198). Several studies have examined this concept, and it is generally accepted that a tool should be tailored to the local
context, language and culture. This is not always feasible. Ideally, questions are not simply translated, but are comprehensively examined and rephrased to match language and culture of the target patient population. The Chinese Geriatric Depression Inventory is an example of such a tool (199). Tools often have different cut offs, depending on the country of use (184). When the CSDD was directly compared between elderly patients in Norway and Brazil, different psychometric properties were observed despite similar baseline prevalence (184). The reasons for these differences include access to care, language, culture, stigma, caregiver resilience, and illness experiences (184).

Cognitive impairment has implications affecting the use of screening tools. The severity of cognitive, language, and executive dysfunction affect the patient’s ability to convey symptoms to achieve tool accuracy (69). Involvement of a caregiver is considered to be crucial in the evaluation of these patients, and is incorporated by the CSDD which is the most accurate tool for dementia (69, 197). This tool was recommended by several guidelines due to superior accuracy and involvement of the collateral (69, 197). However, the CSDD is resource intensive (69, 197). Stress or mood of a caregiver can affect their rating on tools (200). Although practitioner concerns about the effect of cognition on screening tools were well founded, a recent systematic review identified CSDD as an accurate tool for depression detection in dementia (69). In general, evidence is lacking for detection in moderate to severe dementing illness and the differences between different types of dementia (69).

Recommendations related to suicide risk assessment in dementia were divergent between guidelines. Practitioners felt that suicide risk should be screened for, as the risk of adverse outcome is high. Retrospective cohort data of dementia patients has demonstrated that depression is a risk factor for suicide (OR 2.0; 95% 1.5, 2.9) (201). However, there was little agreement on the best approach for this assessment, with most practitioners using clinical history.

There are several other barriers that affect the accuracy of detection. Symptomatic overlap between the different types of depressive illnesses (e.g. grief or adjustment disorder), and overlap with depression and apathy or the neurologic conditions are important barriers to diagnosis. This symptomatic overlap requires time and clinical experience to separate mood symptoms from neurologic illness. Additionally, practitioners found that patients appear to minimize symptoms. This appears to be a complex mixing of behaviours. In part, this is related
to the stigma of the illness, which is well documented in the general population (180). This minimizing of symptoms is also due to differences between cultures (184).

When patients described this behaviour, they did not describe cultural barriers or stigma preventing discussion with physicians. Patients reported difficulty in describing and expressing their symptoms. This is an interesting finding, and one that has not been described before. The importance here is that practitioners need to be actively seeking out these symptoms with patients but also providing education on the possibility of these symptoms. This could serve as a potential area for future study, looking at patient education on the non-motor symptoms in PD and how that may impact their diagnosis and management. Enabling the patient in the implementation of CPGs is an emerging issue (202). A recent meta-review identified 77 studies that looked at self-management interventions that were accompanying components of guidelines (202). They found several targets for patient engagement that were effective, including provision of information (202). The most commonly used was education sessions and online tools, however, both single and multifaceted interventions were effective (202). Having further patient engagement as part of guideline development and future implementation appears to be a effective in improving care outcomes (202).

Expert groups identified another barrier to guidelines use: dementia is a syndrome and not a distinct pathology. This distinction is important, and contributes to possible confusion when interpreting CPG recommendations for dementia in general, as they may not apply to certain specific subtypes. Included guidelines typically refer to Alzheimer’s or vascular dementia, which are common and have the most evidence. This represents a barrier when managing less common or clinically uncertain cases.

An additional barrier is the varied criteria for the diagnosis of depression in dementia. Plural criterion for diagnosis creates heterogeneity in practice due to uncertainty about the utility of different clinical criteria. The three available diagnostic criteria for depression in dementia were compared in a 2010 study, which demonstrated that the DSM and (International Statistical Classification of Diseases and Related Health Problems) ICD-10 criteria were similar for the detection of depression, but that the Provisional Diagnostic Criteria for Depression in Dementia (PDC-dAD) criteria were different (203). The PDC-dAD criteria were adapted from the DSM specifically for dementia by removing questions pertaining to memory, decreasing the number of required symptoms, and shortening the time period (203). The latter two changes contribute to
the PDC-dAD identifying a higher prevalence; however, there was significant agreement among the criteria (203).

Overall, these behaviours relate to the capability domain of the BCW. Key barriers were related to knowledge, beliefs about consequences, psychological skills, and social influences. Several targets for potential implementation interventions were identified, and can be further developed in future work.

4.2.3. Guideline Implementation: Management

When it comes to the management of these disorders, practitioners and patients generally referred to the management of depression; fewer had experience with the treatment of anxiety. Practitioners and patients noted a significant clinical benefit with the use of non-pharmacologic treatments for depression. However, this was not reflected in the recommendations for management of depression in PD. The disconnect is likely related to a lack of evidence at the time of publication. Two studies that found benefit were published after the search dates of the included guidelines (73, 204), which emphasizes the need for frequently updated guidelines.

From the perspective of implementation, access to the many varied therapies represents a challenge. While the precise type of access issue is likely dependent on local context, the global issues of resource management and distribution are not. Here the barriers were cost, physical access, lack of available resources, and restrictions to services because of comorbidity. One additional barrier was the concern that cognitive impairment, depending on severity, can effect the utility of psychotherapy or CBT. However, evidence does support the use of psychotherapy or CBT in mild dementia (77). Non-pharmacologic interventions may benefit patients across the spectrum of severity of disorder, and avoid further side effects, polypharmacy, and drug interactions (77).

Practitioners agreed that pharmacologic therapy is often warranted, but had concerns about the supporting evidence, drug interactions, and side effects. When choosing therapy, practitioners balance the risk of mood disorder with risks of treatment. Many practitioners described this as difficult to manage with limited evidence. These difficulties are described in detail in the discussion of Chapters 2 & 3.

There are also local issues that compound barriers to therapy, such as wait times, inability to provide follow up, short appointment times, or lack of access to multidisciplinary team
members in the clinic. These issues were not uniform, but it was a prominent barrier noted by all groups. To manage these barriers, many specialists provide instructions to the FP to institute a management plan. Patients describe feeling comfortable with their FP providing this care, however there needs to be clearer communication between practitioners.

All participants described the importance of the role of the family practitioner. The specialists describe specifically the need for the family practitioners in having a familiarity with the patients that may enable diagnosis and providing follow up regarding the management of depression or anxiety. Similarly so patients describe their closer relationship with their family practitioners being important to diagnosis and management. Although there may be some concerns about communication and some practitioner beliefs about limitations, this relationship cannot be understated. This is because it provides a target for future guidelines and implementation. The relative availability of the family practitioners over the specialist could enable closer follow up of these patients and familiarity, which can be exploited for improved management of these patients. Clear evidence based guidelines targeted to family practitioners could enable improved detection and management of anxiety or depression in these disorders. Similarly tools to aid in implementation and communication with specialist could aid high quality care. This was corroborated by the family practitioners involved in the study, noting they often manage these patients but do not have available guidelines targeted to them.

Lastly the recommendation about use of cholinesterase inhibitors for depression or anxiety in dementia was surprising to participants. This surprise was perceived to be due to a lack of quality of evidence supporting the recommendation, risk of worsening behavioural symptoms, and risk of adverse events. Experts were concerned that the studies referred to by guidelines typically focused on neuropsychiatric symptoms in general, with depression or anxiety as one of many outcomes (205). These studies were not focused on depression as a primary outcome. One study used a before and after design in a cohort of dementia patients who were depressed or not depressed by DSM criteria at baseline (206). The major outcome was the difference in the GDS at baseline and 16 weeks (206). They found that depressive symptoms on the GDS improved by approximately 2 points (8.6±2.5 to 6.5±3.1, p<0.0001) in depressed patients at 16 weeks, with no difference seen in the Neuropsychiatric Inventory (206). Some concerns with this study relate to the use of the GDS as an outcome measure, wide standard deviations in their estimates and whether a two-point difference is clinically significant.
Overall, the difficulties with the implementation of recommendations for treatment revolved around scarcity of resources and access for non-pharmacologic therapies, and concerns about evidence and efficacy of pharmacologic interventions. The majority of barriers here were under the opportunity component of the COM-B system, related to beliefs about consequences, environmental context, and resources.

4.2.4. Limitations to the Focus Group Study

A limitation to this study was the poor response rate of dementia patients or caregivers. Therefore, we are unable to comment on their experiences with comorbid depression or anxiety. Our recruitment strategy involved distribution of information to patients or caregivers in the form of flyers and posters, but required them to contact the study investigators in order to participate. Unfortunately, we were unable to recruit any dementia patients who met inclusion criteria. Possible contributing factors include the cognitive nature of the underlying disease, perceived burden of participation, or lack of uptake within the clinics. The latter factor was addressed by having constant presence in the clinical areas, and repeated contact with the teams at each clinic. Of note, it was observed that clients of the clinic had the information in their packages, yet did not contact the study investigators. The only way to account for difficulty with patients recalling to contact the team would be to adjust the recruitment strategy during planning stages. In future studies, recruitment strategies will attempt to pre-emptively address this issue.

Of those recruited to the PD patient group, all had a formal diagnosis of depression and none had diagnoses of anxiety. However, they did endorse symptoms of anxiety. This may be tied to the lack of evidence or lower practitioner comfort with anxiety over depression.

Given the size of our center it was feasible to have one focus group per stakeholder category. In this study we were able to recruit almost all eligible specialists for focus groups. The only groups where more practitioners were available were the family practitioners and patients. Given the difficulty with recruiting one group, and the goal of the project to compare across stakeholder groups, only one focus group was targeted per category.

For logistical reasons, we used individual interviews for neurologists in the movement disorders clinic and the associated psychiatrists. The interviews occurred concurrently with focus groups for pragmatic reasons. There were no differences in the question guides or materials provided between groups. When carefully reviewing the content from interviews versus focus
groups, it did not appear that the overall type of information shared differed, participants were no more or less candid, and a similar breadth of information was covered. Focus group and interview data was used as complementary methods and a means to ensure representation of key stakeholders (182).

Five of TDF domains did not match any of the codes: Skills (Physical), Optimism (Automatic or Reflective), Reinforcement, and Intentions. Physical skills such as surgery, are not likely to come up in a discussion of psychiatric illnesses (125). Reinforcement is related to ‘associative intentions’ such as rewards or incentives, and optimism refers to ‘a general disposition’ (127). Given that there is minimal implementation of the guidelines at this time, it is unlikely that reinforcement behaviours would be noted. Although its possible optimism could be described in response to guidelines or there use, it was not discussed. This is perhaps tied to the somewhat negative perceptions physicians had of guidelines in their current state. Similarly these negative perceptions may also explain why intentions, ‘a conscious decision to perform a behaviour…’ was not prominent (127).

The scope of this study was local. By reviewing international guidelines, and the use of a rigorous behaviour framework transferability of our results to other centers is increased. Although some barriers to guideline use may not be transferable due to specific local context, practitioner and patient experiences are more generalizable. Some difficulties experienced in one center, such as access to resources, are not uncommon in other sites. The review of the practice and opinions of practitioners on international guidelines had broad applicability to guideline development and implementation in the future.

4.3. Synthesis

Trying to understand gaps in care is a complex task that is necessary to improve patient care. In the setting of mental illness, there are many known barriers to care. The existence of these barriers in the setting of common neurologic diseases is less clear. This study attempts to illuminate this gap in the care of those with depression or anxiety in the setting of PD or dementia.

Although there are many means to address gaps in care, CPGs represent one of the most widely used in healthcare (97). CPG success is contingent on implementation. Several factors have been identified as key to effective guideline implementation, including the two main
categories of content and format (87). A combination of approaches allows us to understand the content, evidence, and quality of available guidelines; and then to see how the knowledge/end user uses or receives this information. The involvement of stakeholders is key to understanding what specific barriers and facilitators there are to the use and implementation of guidelines. Stakeholder involvement also provides contextual understanding to the use of recommendations in practice.

By using a framework of behaviour theory to examine guideline use and implementation in practice, we are able to better understand what drives associated clinical behaviours. This approach identifies target interventions for behaviour change.

Another key component is evaluation of available evidence, and determination of the state of readiness of evidence for implementation. Readiness for implementation is a complex interaction between evidence and the behaviours of the stakeholder and organization (87). Evidence is evaluated from the perspective of guidelines and stakeholder behaviours. Although evaluating the evidence at the individual level, study is important to establishing the quality of evidence. By examining the guidelines, we see how evidence is summarized for practitioners.

Through systematic review, we have identified 17 high quality guidelines that refer to the care of dementia or PD patients with depression or anxiety. These CPGs provide a range of recommendations for the diagnosis and management of comorbid depression or anxiety with varied levels of evidence and quality of CPG.

4.3.1. Lack of Evidence for the Diagnosis and Management of Anxiety

Firstly, there is a paucity of available evidence for the diagnosis and management of anxiety in PD or dementia. There were few recommendations here, and most of those identified discuss the lack of evidence. One provided expert opinion on screening anxiety in dementia. Only one provided a recommendation for management, which advocated for the use of a cholinesterase inhibitor in dementia patients. Clearly, there is little guidance for practitioners with patients who experience these symptoms, and this leads to uncertainty and variation in care.

This was also displayed in the focus groups, where practitioners stated a lack of comfort and evidence for anxiety diagnosis and management. When examining behaviours associated with the use of these recommendations for anxiety, we see only a few practitioners using anxiety tools. Other practitioners noted the lack of anxiety tools available. Although patients in the focus
groups had symptoms of anxiety, it appeared that few had a formal diagnosis related to their anxiety.

Overall guidelines for anxiety in PD or dementia at this time are not useful clinically because there is so little content. Before recommendations for anxiety in PD or dementia can be of utility, there needs to be significant generation of evidence for both diagnosis and management.

4.3.2. Lack of Clarity Around the Evidence for the Diagnosis Depression

Participants were clear that the diagnosis of depression in PD or dementia is important, but there was less clarity about how to approach this. Five guidelines provided recommendations for the use of screening tools in dementia, and two in PD. These were good practice points to evidence from diagnostic accuracy and prospective studies. The major concerns of clinicians pertained to accuracy of tools and evidence supporting these. There is clear evidence to support the use of screening tools over history alone. Although the systematic reviews of these tools were only recently completed, most of the evidence supporting the tools was well within the target dates of the guidelines. A few of the primary studies were completed in 2011-2013 and may not have been captured in guideline searches.

Two issues may have contributed to this: evidence behind the recommendation was not clear in the CPG, or evidence was not identified. Only one CPG recommending depression screening in PD overlaps with the systematic review of tools; the other references used examine original validation studies of the tools, which were not all for PD. This provides an interesting point for discussion. Practitioners think of guidelines as identifying primary literature and providing background. Based on this study, it is evident that the guideline groups were not identifying the breadth of available evidence at the time for each issue, such as depression screening. One could argue the guideline came to the same conclusion as the systematic review; however, practitioners were unclear on the evidence supporting guidelines. Practitioners stated that they wanted more clear evidence on which tools were accurate in PD or dementia.

Individual search quality and evidence synthesis behind guidelines are crucial. Given the breadth of most guidelines, it may be difficult to capture each subset of a problem in the same detail as a focused systematic review.
There is evidence available to support the screening of depression in these disorders, and there are several opportunities to improve implementation. First, future guidelines should have clear evidence tables with the studies supporting the recommendation laid out to demonstrate validity and improve the usability. Second, the creation of decision support tools or diagnostic clinical pathways to facilitate the use of these tools clinically should be considered.

4.3.3. Variability in the Evidence for Treatment of Depression

According to our stakeholders/end users, the primary intervention for depression in either PD or dementia was non-pharmacologic management. Non-pharmacologic therapy was described as clinically effective across all groups, with different therapies applying to each case. And as discussed above, was clearly recommended in the dementia guidelines but not PD CPGs. So there appears to be a disconnect between the guidelines and clinical practice that highlights the need for updated guidelines. Ideally, guidelines would consider expert opinion, smaller studies, evidence outside of the medical literature, or qualitative literature in certain fields. Perhaps the role and effectiveness of non-pharmacologic interventions would be better addressed by ensuring multidisciplinary team or stakeholder representation during the guideline creation process.

Guidelines recommend the use of anti-depressants for treatment in PD and dementia, however all practitioners were cautious due to mixed or minimal evidence. For example, the level of evidence varied from Grade 2A to Expert Opinion or Inconsistent for the use of anti-depressants in dementia. For PD and dementia, TCAs or SSRIs were suggested, but side effects are an important risk. This was clearly discussed in the expert focus groups as a concern for therapy, with experts indicating their concern that there was little evidence to support treatment. Additionally, there were concerns about recent evidence and the use of TCAs, as discussed previously in Chapter 2 and Section 4.2. There were also concerns that any evidence would not apply to the target population cared for by some practitioners, such as long-term care patients.

This variation in evidence for depression management creates uncertainty in the clinical setting, which is demonstrated by the varied reports of practitioners. This contributes to the under-treatment of depression in these disorders. Without clear evidence or useful recommendations, we will continue to see heterogeneity in practice.
4.3.4. Lack of Stakeholder Involvement Impacts Implementation of Guidelines

The lack of stakeholder involvement in guideline creation directly impacts the implementability of CPGs. Stakeholders have the potential to contribute to the content and format of guidelines. When considering the make up of a guideline committee, there are no formal rules. In an area such as mental health, one would expect a broad multidisciplinary group. Most guidelines included different physicians, and occasionally representative of the multidisciplinary team. Few included patients or patient advocacy groups. It is clear from the focus groups that participants have ideas for guideline improvement or tailoring that could be incorporated at the development stage.

Stakeholders should be involved as part of the guideline group, including patients, members from the multidisciplinary team, and physicians (92). A systematic review examined patient involvement in guidelines, and identified that their involvement in the process promoted improved implementation, comprehensiveness, incorporating values, and positive public influence (92, 207). Other reasons for involvement of patients are to provide evidence, views and experience when evidence is insufficient, to be involved in recommendation creation, to ensure a transparent process, to ensure usability, and to help as part of policy creation (208). An additional benefit is the perception that initial stakeholder involvement increases the ownership of a broader group that is willing to be engaged later on in implementation (94, 208). The inclusion of a broader stakeholder group should improve the implementation of guidelines by providing context, content, transparency, and ownership. This review also cited the legal implications of excluding certain bodies such as pharmaceutical companies (208). The review identified many different ways to include stakeholders; as part of the development group, by submitting evidence, or commenting on the guideline drafts (92, 207, 208). It is key that they are part of the discussion in a meaningful way, to do so they may need education and training (92, 208).

Local groups such as patient engagement researchers would be valuable to the creation of guidelines by providing unique perspectives that are important to the understanding of the condition and associated burdens (209). This was also seen in the focus groups, where patient perspective added detail and understanding to certain practices, such as difficulty describing symptoms. Greater understanding of the patient illness experience enables practitioners to tailor practice and improve care.
4.3.5. Do We Wait For Evidence?

With minimal evidence available, how can we generate recommendations? Creating evidence is important, but requires time and resources. However, lack of evidence does not justify inaction while patients suffer inconsistent care. Consensus methods, such as the Delphi technique, offer a solution that could help create clinical expert opinion recommendations using a rigorous methodology (191). This strategy provides clear recommendations for practitioners, and offers practices that warrant study and serve as a jumping off point for care and research. These methods do not have to be used in isolation from evidence, but could be complementary. Additionally, these types of methods are thought to be generalizable because they are typically created by practitioners working in context (191).

Methods such as the Delphi technique have been used in low income or minority groups to create recommendations when evidence generation is not feasible or practical (191). This was raised as an idea in the neurologist and geriatric psychiatrist focus groups as an acceptable way to generate practice recommendations. This is not the position of all guideline organizations (94). Some organizations would argue that low quality evidence recommendations have inherent risk (94), as it is possible that the recommendation is erroneous when investigated by further study (94). If a consensus approach to recommendation generation is adopted, it would be prudent to evaluate the risk of each intervention as part of the discussion. Consensus methods should not replace evidence if it is present, or prevent further acquisition of evidence. These methods serve as a form of bridging evidence gaps until sufficient evidence is generated.

4.3.6. Formatting, Language and Awareness.

Major barriers to guideline use, such as awareness and format, should be addressed. This is a common theme across guidelines, especially when it comes to language (94, 194). When examining this in the focus groups, it was identified that participants had concerns about vague or confusing language. This issue is ongoing, and often relates back to the uncertainty of evidence (94, 194). When examined in guidelines used by family practitioners, clear statements were followed by 67% and vague by 35% (210). Guideline organizations propose that statements should be actionable –however here again there is a balance between the needs of practitioners and the evidence (194). Studies show that practitioners want clear and direct statements, but the
evidence is rarely that well defined (94, 194). Guidelines committees often stop at available evidence, and thus recommendations remain vague (94).

Focus groups identified that vague statements affect the ability of practitioners in decision-making processes. Michie and Johnston (2004), suggest that making guideline language behaviourally oriented could be the simplest intervention for improving guideline implementation (194). It was suggested that simply rephrasing recommendations to specify the related behaviour could achieve higher uptake of recommendations (194). This was a suggestion supported by behaviour theory (194). Basic features of a recommendation, what, who, when, how, and where, could be re-phrased to behavioural terms and increase relatability of recommendations (194). Re-phrasing guideline statements to be behaviour or action oriented could improve guideline uptake with minimal resources, and ensure clearer communication of intended outcomes (194).

The format of guidelines also varies between organizations. In some cases, this variation made identification of components of the AGREE II evaluation difficult in the systematic review. Practitioners noted that long and poorly formatted guidelines are not useful in practice. As part of stakeholder involvement, a review of format(s) for CPGs is crucial. For example, the format for a guideline targeting specialist practice is different to that of a family practitioner, and those adaptability concerns could be addressed during guideline development (87). Several strategies to improve formatting include creating multiple versions, websites, e-tools, or review papers. Methods for improving guideline awareness and dissemination could be mapped out better across a multidisciplinary group (92).

Format is a component of guideline creation that can drastically effect implementation. Proper evaluation by stakeholders, use of key behavioural terms, and improving access will all increase success during implementation.

4.3.7. External Barriers Effects the Continuum of Management

Both practitioners and patients are faced with the challenge of scarcity of needed services. Commonly, barriers to clinical activities are external and related to cost or resources (45). Numerous physical and access barriers were noted to diagnosis of these comorbidities. Physical and access barriers were even more significant in management of these comorbidities. In some cases, access issues permeated all aspects of depression care. One example of this was
access to exercise therapy. Environmental barriers such as these are described across studies often citing a lack of time, staff or support (45). However, it was also identified that comorbid neurologic diagnosis further restricts access to service for patients. This could reflect stigma to the neurologic condition, or concerns about efficacy of the intervention.

There are many opportunities to address these barriers. Perhaps the simplest intervention is a clear review of available services and the processes to access them. Within one focus group, there were disparate descriptions of whether access to a service was available in dementia. If a gap in access is identified and there is evidence to support the use of a tool/intervention, then discussions about locating resources needs to occur. Issues of external barriers are specific to the local context. By reviewing the efforts of other regions, one could identify previously effective strategies to adapt locally.

4.4. Conclusions

There are multiple guidelines available that cover, however briefly, the intersection between PD or dementia and anxiety or depression. Within guidelines, areas that warrant improvement include stakeholder involvement, implementation plans, updating procedures, and editorial independence. This builds on recent evidence regarding guideline quality and implementation.

Unique to this study is the systematic review of all available international guidelines, prior to an assessment of barriers and facilitators. This provides a broad background and international context to inform this assessment. Although guideline recommendations are available, there are many barriers to their use and implementation. The primary concern of participants was the lack of quality evidence to inform practice. The use of guidelines was also hindered by impractical, out of date, or vague recommendations. Implementation of guidelines were influenced by several factors, including concerns about accuracy of screening tools, symptomatic overlap, beliefs about limitations to their practices, external barriers, and risk of pharmacologic therapy. Given the significant effects of depression or anxiety on those with PD or dementia, further work is needed to generate evidence and improve guideline implementation.

This evidence identifies that there are gaps in guideline quality and guideline evidence that effect their use and implementation. In cases where perhaps there is better evidence for example screening – practitioners are still not following these recommendations due to concerns
about the validity of evidence behind them. All participants agree that treatment is necessary and favour non-pharmacologic therapy. Although evidence and recommendations here vary in guidelines, since their publication there has been more favourable evidence. And although there is some evidence for pharmacologic treatment, practitioners are leery of the quality of evidence and potential adverse effects.

Guidelines have a role in improving care and reducing gaps in knowledge but they can only do so when the evidence is clearly explained and linked to guidelines. In order to improve diagnosis and treatment for these patients first there must be further quality evidence generated. Followed by more rigorous guideline creation with emphasis on improving stakeholder involvement and applicability.

4.5. Future Directions

4.5.1. Stakeholder Meeting to Plan Interventions that Address Barriers and Facilitators to Guideline Implementation

The immediate objective following this research will be to address Objective 3—Start Selecting, Tailoring and Developing Knowledge Translation Interventions of the grant supporting this research. The plan for this meeting is as follows.

4.5.1.1. Meeting Objective

To facilitate a stakeholder meeting to disseminate and discuss research findings; and start to plan knowledge translation interventions based on the findings of objectives 1 and 2.

We will hold a meeting with national/local stakeholders (including patients) to present our findings and start developing a plan to address this knowledge-to-practice gap. We will recruit stakeholders through local contacts as outlined Table 2: Recruitment Plan, and national contacts identified through the research team, SCN and other collaborators. The outcome of this meeting will be a preliminary plan to address this knowledge-to-practice gap and start to consider an intervention that addresses identified barriers.
4.5.1.2. Stakeholders.

This project is aimed at several stakeholders in the continuum of care for adults with comorbid depression/anxiety and dementia or Parkinson’s disease. The results of this study will be of interest to knowledge-/end-users (clinicians) involved in the frontline care for these patients. Another crucial target is the adult and their family caregivers (end-users). It has been shown that patients with greater health knowledge achieve better outcomes, for example, knowledge of the available treatments for depression may reduce stigma associated with the disease and lead a person to seek help (211). In addition to clinicians, we hope to provide adults with dementia or Parkinson’s disease and their family caregivers with high quality health knowledge around the diagnosis and treatment of comorbid depressive and anxiety disorders.

4.5.1.3. Meeting Plan.

Key messages from our findings in Objective 1 and 2 will be disseminated along with a meeting agenda a priori. The key messages to be distributed ahead of time will be determined in conjunction with local stakeholders. The meeting will be chaired by ZG, and JHL with participation from the other members.

This meeting will take place in Calgary, and will include researchers, clinicians, patients, caregivers, policy makers, and related organizations.

At the first part of the meeting we will present the review results, along with an overview of identified barriers and facilitators to guideline implementation. The focus of the meeting from there on in will be the initial formulation, as a group, of a plan. This will be done through a series of group decision-making activities using techniques such as the World Café (212). The World Café method has been used in many instances to help facilitate discussion in a large group of multidisciplinary members (212). For example Teut et al. used this method to examine the use of complementary and alternative medicines in dementia care (213). This method focuses on seven principles; setting context, creating hospitable space, exploring questions that matter, encouraging contributions, connecting diverse perspectives, listen together for patterns and insights, and sharing collective discoveries (212, 214). Where a key advantage of this method is the open collaboration, knowledge sharing, and large group participation (212, 213). Following this, the results from the meeting will be synthesized into an initial report –to allow for further
discussion around priority setting. These preliminary discussions will develop the early plans towards developing an implementation strategy.

4.5.1.4. Meeting Outcomes

Using the evidence generated from Objectives 1 & 2 to inform Objective 3 provides a rigorous foundation for the further research development. One of the first outcomes from Objective 3 will be to develop a plan to address the identified behaviours behind the barriers and facilitators to guideline implementation in this area. Using the aforementioned BCW as it maps on to interventions we will be able to identify and recommend several target interventions. These interventions need to be tailored to the local context. Further, we will be able to build on the identified barriers to the use of the guidelines themselves and aim to inform further guideline development in the area. Overall the deliverables of this meeting will be to develop a plan to address this evidence-to-practice gap and to start to develop an implementation intervention that considers the identified barriers.

4.5.1.5. Main topics for Stakeholder Meeting.

The identified evidence gaps and concerns about evidence quality will be considered at the stakeholder meeting. A sequential approach from diagnosis towards management would ensure that former aims help develop future ones.

Given the evidence from the previous studies the topics for review within the stakeholder meeting will focus on:

1. Planning further research aims (Knowledge Inquiry/Synthesis) to address the gaps in evidence for the diagnosis and management for anxiety in PD or dementia.
2. Planning implementation aims based on the BCW & TDF for the evidence surrounding the screening and diagnosis of depression in PD or dementia (Select, tailor, implement interventions).
3. Planning further study or implementation aims for the management of depression in PD or dementia (Knowledge Inquiry/Synthesis)

The work of the stakeholder meeting aims to develop a plan for further study through critical evaluation of the work contained in this thesis and the BCW. By doing so we aim to
create a comprehensive plan for subsequent projects to address identified gaps in the evidence and barriers to guideline use. The work of this group will be synthesized into a ‘White Paper’ and inform a research program going forward. Given that the future projects are being identified in this meeting through a comprehensive review and group discussion, we have not presented any specific other projects here.

There is a knowledge-to-practice gap for patients with dementia or PD and comorbid depression or anxiety. Two activities addressed the gap by synthesising the existing knowledge and assessing the determinants of use of the knowledge, the findings inform the future development of knowledge translation interventions as well as further knowledge inquiry ultimately improving the care among older adults with dementia or PD and comorbid depression or anxiety.
References.


139. Canada’s Strategy for Patient-Oriented Research. Ottawa, Ontario Canadian Institutes of Health Research; 2011.
166. Guidance notes for registering a systematic review protocol with PROSPERO. PROSPERO: International prospective register of systematic reviews Centre for Reviews and Dissemination, National Institute for Health Research; 2013.


177. Goodarzi Z, B Mele, S Guo, H Hanson, N Jette, S Patten, T Pringsheim and J Holroyd-Leduc. Guidelines For Dementia or Parkinson’s Disease with Depression or Anxiety: A systematic review. Campus Alberta Neurosciences Meeting; Banff2016.


Appendices.

Appendix A. Database Specific Search Strategies for Systematic Review.

<table>
<thead>
<tr>
<th>Dementia &amp; PD Concepts</th>
<th>Depression Concepts</th>
<th>Anxiety Concepts</th>
<th>Guideline Concepts</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Keywords</strong> (title/abstract words)</td>
<td><strong>Keywords</strong> (title/abstract words)</td>
<td><strong>Keywords</strong> (title/abstract words)</td>
<td><strong>Keywords</strong> (title/abstract words)</td>
</tr>
<tr>
<td><em>Parkinson</em></td>
<td><em>Depression</em></td>
<td><em>anxious</em></td>
<td><em>Guideline</em></td>
</tr>
<tr>
<td><em>Dementia</em></td>
<td><em>Depressive</em></td>
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<tr>
<td><em>alzheimer</em></td>
<td><em>depressed</em></td>
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<tr>
<td><em>frontotemporal</em></td>
<td><em>mood disorder</em></td>
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<tr>
<td><em>lewy bod</em></td>
<td><em>MeSH Terms</em></td>
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<tr>
<td><em>huntington</em></td>
<td><em>Depression</em></td>
<td><em>Anxiety</em></td>
<td></td>
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<tr>
<td><em>primary progressive aphasia</em></td>
<td><em>Depressive disorder</em></td>
<td><em>Anxious</em></td>
<td></td>
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<tr>
<td><em>creutzfeld-jakob</em></td>
<td><em>Depressive disorder, Major</em></td>
<td><em>Anxiety Disorders</em></td>
<td></td>
</tr>
<tr>
<td><strong>MeSH Terms</strong></td>
<td><strong>EMTree Terms</strong></td>
<td><strong>PsycInfo Terms</strong></td>
<td><strong>MeSH Terms</strong></td>
</tr>
<tr>
<td><em>Dementia</em></td>
<td><em>Depression</em></td>
<td><em>Anxiety</em></td>
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<tr>
<td><em>Alzheimer’s Dementia</em></td>
<td><em>Major depression</em></td>
<td><em>Anxiety Disorder</em></td>
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<tr>
<td><em>Vascular Dementia</em></td>
<td><em>Atypical Depression</em></td>
<td><em>“mixed anxiety and depression”</em></td>
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<tr>
<td><em>Multi-infarct Dementia</em></td>
<td><em>Endogenous Depression</em></td>
<td><em>Anxiety</em></td>
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<tr>
<td><em>Frontotemporal Dementia</em></td>
<td><em>Late Life Depression</em></td>
<td><em>Neurosis</em></td>
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<td><em>Lewy Body Disease</em></td>
<td><em>Long Term Depression</em></td>
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<tr>
<td><em>Parkinson Disease</em></td>
<td><em>Masked Depression</em></td>
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<tr>
<td><em>Parkinsonian Disorders</em></td>
<td><em>Reactive Depression</em></td>
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<tr>
<td><em>CADASIL</em></td>
<td><em>Treatment Resistant Depression</em></td>
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<tr>
<td><em>Primary Progressive Aphasia</em></td>
<td><em>Depression</em></td>
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<tr>
<td><em>Huntington Disease</em></td>
<td><em>Agitated Depression</em></td>
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<td><strong>EMTree Terms</strong></td>
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<td><em>Parkinson Disease</em></td>
<td><em>Organic Depression</em></td>
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<td><em>Parkinsonism</em></td>
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<tr>
<td>“Frontal Variant”</td>
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<td><em>Frontotemporal Dementia</em></td>
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<td><em>Dementia</em></td>
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<td><em>Alzheimer Disease</em></td>
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<td><em>Multiinfarct Dementia</em></td>
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<td><em>Frontotemporal Dementia</em></td>
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<td><em>Dementia</em></td>
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<td><em>Semantic Dementia</em></td>
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<td><em>Presenile Dementia</em></td>
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<td><em>Pick Presenile Dementia</em></td>
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<tr>
<td><em>Dementia</em></td>
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<tr>
<td>CADASIL</td>
<td>&lt;br&gt;Primary Progressive Aphasia &lt;br&gt;Lewy Body &lt;br&gt;Creutzfeldt Jakob Disease</td>
<td>&lt;br&gt;Quality Assurance &lt;br&gt;Quality Improvement &lt;br&gt;‘Quality Indicators, Health Care’ &lt;br&gt;EMTree Terms &lt;br&gt;Practice Guideline &lt;br&gt;Clinical Pathway Standard &lt;br&gt;Clinical Protocol Professional Standards Evidence Based Practice Evidence Based Medicine Health Care Quality Control Quality Assurance &lt;br&gt;EMTree Terms Treatment Guidelines Professional Standards Evidence Based Practice “Quality of Care”</td>
<td>&lt;br&gt;Psycinfo terms</td>
</tr>
</tbody>
</table>
Appendix B. Components of the AGREE II Tool

The AGREE II tool is 23 items within 6 domains. Each domain is focused on a component of guideline quality. A quality score is independently calculated for each of the domains.

<table>
<thead>
<tr>
<th>Domain</th>
<th>Goal</th>
<th>Questions</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Scope and Purpose</td>
<td>Overall aim of the guideline, target group</td>
<td>1. The overall objective of the guideline is (are) specifically described.</td>
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<tr>
<td></td>
<td></td>
<td>2. The clinical question(s) covered by the guideline is (are) specifically described.</td>
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<tr>
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<td></td>
<td>3. The patients to whom the guideline is meant to apply are specifically described.</td>
</tr>
<tr>
<td>2. Stakeholder Involvement</td>
<td>Extent to which stakeholders were involved in developing the guideline and represents the views of its intended users</td>
<td>4. The guideline development group includes individuals from all the relevant professional groups.</td>
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<tr>
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<td>5. The patients’ views and preferences have been sought.</td>
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<td>6. The target users of the guideline are clearly defined.</td>
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<td>7. The guideline has been piloted among target users.</td>
</tr>
<tr>
<td>3. Rigor of Development</td>
<td>Process of gathering and summarizing the evidence, methods used to develop recommendations</td>
<td>8. Systematic methods were used to search for evidence.</td>
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<td>9. Criteria for selecting the evidence are clearly described.</td>
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<td>10. The methods used for formulating recommendations are clearly described.</td>
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<td>11. The health benefits, side effects and risks have been considered in formulating the recommendations.</td>
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<td>12. There is an explicit link between the recommendations and the supporting evidence.</td>
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<td>13. The guideline has been externally reviewed by experts prior to its publication.</td>
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<td>14. A procedure for updating the guideline is provided.</td>
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<tr>
<td>4. Clarity of Presentation</td>
<td>Language, structure, format of guideline</td>
<td>15. The recommendations are specific and unambiguous.</td>
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<td></td>
<td>16. The different options for management of the condition are clearly presented.</td>
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<td>17. Key recommendations are easily identifiable.</td>
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<td>18. The guideline is supported with tools for application.</td>
</tr>
</tbody>
</table>

5. Applicability
Potential barriers and facilitators to implementation, strategies to improve uptake, resources needed to implement the guideline

19. The potential organizational barriers in applying the recommendations have been discussed.
20. The potential cost implications of applying the recommendations has been considered.
21. The guideline presents key review criteria for monitoring/or audit purposes.

6. Editorial Independence
Process of gathering and summarizing the evidence, methods used to develop recommendations

22. The guideline is editorially independent from the funding body.
23. Conflicts of interest of guideline development members have been recorded.
## Appendix C: Extracted Statements from Guidelines for Parkinson’s Disease

### Statements & Recommendations for Parkinson's Disease (PD)

#### Anxiety

<table>
<thead>
<tr>
<th>Evidence for the diagnosis and treatment of Anxiety in PD is lacking.</th>
</tr>
</thead>
<tbody>
<tr>
<td>“There is insufficient evidence to support or refute the treatment of anxiety in PD with levodopa (Level U).” <em>Zesiewicz et al.</em> (2010)</td>
</tr>
<tr>
<td>“Data regarding the treatment of anxiety in PD are insufficient.” <em>Zesiewicz et al.</em> (2010)</td>
</tr>
<tr>
<td>“The lack of sufficient research in the management of these additional problems [anxiety] prevents us from providing additional recommendations” <em>Grimes et al.</em> (2012)</td>
</tr>
<tr>
<td>“Although randomized controlled trials of antianxiety agents in patients with PD are lacking, their pharmacologic action and widespread clinical use are consistent with benefit in anxiety. Anti-anxiety medications have been associated with ataxia, falls, and cognitive dysfunction.” <em>Zesiewicz et al.</em> (2010)</td>
</tr>
</tbody>
</table>

#### Depression

<table>
<thead>
<tr>
<th>Using a validated tool to screen for Depression in PD is recommended.</th>
</tr>
</thead>
<tbody>
<tr>
<td>“Self-rating or clinician-rated scales may be used to screen for depression in patients with Parkinson’s disease. (Level C)” <em>Grosset et al.</em> (2010)</td>
</tr>
<tr>
<td>“An assessment of neuropsychological functioning in a person presenting with parkinsonism suspected of being PD is recommended (Level A) and should include: A collateral history from a reliable carer, A brief assessment of cognition, Screening for REM Sleep Behavior Disorder (RBD), psychotic manifestations and severe depression.” <em>Berardelli et al.</em> (2013)</td>
</tr>
<tr>
<td>“When clinician-rated assessment is possible, the Hamilton Depression Rating Scale or the Montgomery-Asberg Depression Rating Scale should be used to establish the severity of depressive symptoms. (Good Practice Point (FPP))</td>
</tr>
<tr>
<td>1. Diagnosis of depression should not be made on the basis of rating scale score alone.</td>
</tr>
<tr>
<td>2. Assessment/formulation of depression should be carried out via clinical interview, with a focus on low mood, and with due caution in relation to interpretation of cognitive/somatic symptoms that may be symptoms of Parkinson’s disease rather than depression.</td>
</tr>
<tr>
<td>3. Relatives or carers who know the patient well should be invited to provide supplementary information to assist the diagnosis, particularly in the context of cognitive impairment.” <em>Grosset et al.</em> (2010)</td>
</tr>
<tr>
<td>“Part I (Non-Motor Aspects of Experiences of Daily Living) of the MDS-UPDRS includes validated screening questions for hallucinations and psychosis, as well as depressed mood, and is recommended as a ‘clinician-friendly’ screening instrument (Class 1)” <em>Berardelli et al.</em> (2013)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Practitioners should have a low threshold for diagnosing Depression in PD.</th>
</tr>
</thead>
<tbody>
<tr>
<td>“Clinicians should have a low threshold for diagnosing depression in PD. (NICE R59 Level D) (FPP)” <em>Grimes et al.</em> (2012)</td>
</tr>
<tr>
<td>“Clinicians should be aware that there are difficulties in diagnosing mild depression in people with PD because the clinical features of depression overlap with the motor features of PD. (NICE R60 Level D) (FPP)” <em>Grimes et al.</em> (2012)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Treatment of Depression in PD needs to be individualized to each case.</th>
</tr>
</thead>
<tbody>
<tr>
<td>“The management of depression in people with PD should be tailored to the individual, in particular, to their co-existing therapy. NICE R61 Level D (FPP)” <em>Grimes et al.</em> (2012)</td>
</tr>
</tbody>
</table>
**Anti-depressant Therapy is recommended; there is little evidence to suggest one agent over another.**

“In clinical practice a wide range of antidepressant medication is available with an established evidence base for the efficacy in treatment of major depressive illness although this has not been replicated within the limited range of studies in patients with depression in Parkinson’s disease. It is not possible to make a specific recommendation for pharmacological treatment of depression in patients with PD.” **Grosset et al. (2010)**

“There is no evidence favoring any particular antidepressant medication from the standpoint of therapeutic efficacy and safety for patients with Parkinson’s disease complicated by major depressive disorder” **Gelenberg et al. (2010)**

**Tricyclic Antidepressants & SSRI’s have some evidence for treatment, but this must be balanced with the adverse effects.**

“Amitriptyline may be considered in the treatment of depression associated with PD (Level C)” **Grimes et al. (2012)**

“The theoretical benefits of the antimuscarinic effects of some of the tricyclic agents in the treatment of patients with major depressive disorder with Parkinson’s disease are offset by the memory impairment that may result.” **Gelenberg et al. (2010)**

“Whilst there is some evidence for the effectiveness of tricyclic antidepressants (amitriptyline and desipramine), the importance of this is offset by adverse effects and the short term follow up in the relevant RCTs.” **Grosset et al. (2010)**

“Selective Serotonin Reuptake Inhibitors (SSRIs) were suggested to be beneficial in uncontrolled studies (Class II-IV). However, in placebo-controlled studies, no SSRIs (paroxetine, citalopram, sertraline and fluoxetine) were clearly demonstrated to be effective, which may be owing to study design and large effect sizes on placebo.” **Ferreira et al. (2013)**

“One placebo-controlled study (Class II) showed improvement on nortriptyline, and another found improvement with desipramine and citalopram (Class II). A placebo-controlled trial in 52 patients found nortriptyline but not paroxetine to be efficacious. A small, single-blind study found improvement with sertraline but not amitryptiline.**

**Newer antidepressants.** A Class II study found improvements with fluoxetine. There is insufficient evidence from a small study of atomoxetine.” **Ferreira et al. (2013)**

“In individuals with Parkinson’s disease, the choice of an antidepressant should consider that serotonergic agents may worsen symptoms of the disease (Level II)” **Gelenberg et al. (2010)**

“Bupropion has potential dopamine agonist effects (benefitting symptoms of Parkinson’s disease but potentially worsening psychosis) (Level II) “ **Gelenberg et al. (2010)**

“Most antidepressants, especially SSRIs and mirtazapine, may worsen RLS, PLM and RBD (Class IV).” **Ferreira et al. (2013)**

**Certain agents such as Amoxapine or Lithium should be avoided due to worsening of PD Symptoms.**

“Amoxapine, an antidepressant medication with dopamine-receptor-blocking properties, should be avoided for patients who have Parkinson’s disease.” **Gelenberg et al. (2010)**

“Lithium may, in some instances, induce or exacerbate parkinsonian symptoms.” **Gelenberg et al. (2010)**

**There is some evidence for the use of dopamine agonists & MAOI for depression, but not for levodopa.**

“Levodopa. There are no studies on the effects of chronic levodopa on depression in PD.” **Ferreira et al. (2013)**
There is not sufficient evidence in the literature to suggest treatment with levodopa will improve depression and only weak support for the efficacy using the dopamine agonist pramipexole. There have been anecdotal reports of the MAO-B medication selegiline helping depression but this has yet to be confirmed in adequate studies. In general when symptoms of depression are confined to ‘off time’ they may respond well to any treatment that will reduce fluctuations and improve ‘on time’.” Grimes et al. (2012) “Dopamine agonists. A small 8-month study found improvement with pergolide and pramipexole (Class III). A meta-analysis had suggested an antidepressant effect of pramipexole in PD, which was confirmed in a placebo-controlled study, where most of the improvement was attributable to a direct antidepressant rather than a motor effect (Class I).” Ferreira et al. (2013)

“Selegiline has antiparkinsonian and antidepressant effects but may interact with L-dopa and with other antidepressant agents (Level I).” Gelenberg et al. (2010)

There is insufficient evidence regarding the use of ECT, TCMS and psychotherapy in depression with PD.

“There is insufficient data for electroconvulsive therapy, repetitive transcranial magnetic stimulation and psycho-therapy in PD.” Ferreira et al. (2013)

“Electroconvulsive therapy exerts a transient beneficial effect on the symptoms of idiopathic Parkinson’s disease in many patients; however, it might occasionally worsen L-dopa-induced dyskinesias and induce a transient interictal delirium, which necessitates reductions in doses of dopamine agonist medications” Gelenberg et al. (2010)

“ECT remains a potentially lifesaving treatment in major depression and has been used successfully in PD but sufficient trials in PD depression do not exist.” Grimes et al. (2012)
<table>
<thead>
<tr>
<th>Appendix D: Extracted Statements from Guidelines for Dementia</th>
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</thead>
<tbody>
<tr>
<td><strong>Statements &amp; Recommendations for Dementia</strong></td>
</tr>
<tr>
<td><strong>Anxiety</strong></td>
</tr>
<tr>
<td>There is little evidence about the diagnosis or treatment of Anxiety in those with Dementia.</td>
</tr>
<tr>
<td>“The Hamilton Anxiety Depression (HAD) is an assessment instrument that quantifies anxiety &amp; depression (Level 4)”</td>
</tr>
<tr>
<td>“There is not enough evidence to make recommendations about the treatment of anxiety in dementia.” AQuAs (2010)</td>
</tr>
<tr>
<td><strong>Depression</strong></td>
</tr>
<tr>
<td>Patients experiencing Dementia should be evaluated for Depression.</td>
</tr>
<tr>
<td>“At the time of diagnosis of dementia, and at regular intervals subsequently, assessment should be made for medical comorbidities and key psychiatric features associated with dementia, including depression…” NICE (2011)</td>
</tr>
<tr>
<td>“Care packages for people with dementia should include assessment and monitoring for depression and/or anxiety.” NICE</td>
</tr>
<tr>
<td>“…depressive symptoms are common in dementia, particularly in vascular dementia, FTD and PDD and neurologists should be trained to recognize depressive disorders.” Sorbi et al. (2012)</td>
</tr>
<tr>
<td>“Assessment of behavioral and psychological symptoms [including depressive symptoms] of dementia is essential for both diagnosis and management, and should be performed in all patients (Level A).” CRCD (2011)</td>
</tr>
<tr>
<td>“Behavioral and psychological symptoms [including depressive symptoms] often have somatic co-morbidity or complications. A possible causative co-morbidity or complication should be [considered]. (Level A)” CRCD (2011)</td>
</tr>
<tr>
<td>“When behavioral disturbances like … depressed mood accompany [dementia] possible other causes have to be ruled out, (Grade 3).” Ihl et al. (2011)</td>
</tr>
<tr>
<td>“In people with advanced dementia at end-of-life stage … the diagnosis of depression must be based on the clinical observation, the information provided by relatives and, if possible, the use of specific scales. (Level D)” AQuAs (2010)</td>
</tr>
<tr>
<td>“The evidence is inconclusive regarding dementia and suicide risk” Avalia-T (2012)</td>
</tr>
<tr>
<td>“Patients with depression [in dementia] should be evaluated for suicide risk [I].” APA (2010)</td>
</tr>
<tr>
<td><strong>Use of a valid screening tool (e.g. CSDD or GDS) for Depression is recommended.</strong></td>
</tr>
<tr>
<td>“The 19-item Cornell Scale for Depression in Dementia (CSDD) has the best sensitivity (93%) and specificity (97%). A cutoff of greater than or equal to six identifies depression in a demented population [Low Quality Evidence]). This is a clinician-administered tool to help diagnose depression in patients with dementia.” Mitchell et al. (2013)</td>
</tr>
<tr>
<td>“One screening tool is the Cornell Scale for Depression in Dementia, which incorporates self-report with caregiver and clinician ratings of depressive symptoms” APA (2010)</td>
</tr>
<tr>
<td>“The CSDD is based on combined caregiver and patient interviews. The 15-item geriatric depression scale has also been validated for use in AD but the CSDD appears to be a more sensitive and specific tool for detecting depression independently of the severity of dementia.” Hort et al. (2010)</td>
</tr>
<tr>
<td>“More focused scales evaluating specific symptoms as well as possible treatment complications of some non-AD dementias have been available, including the assessment of depression (GDS-15, CSDD)...(Class II).” Sorbi et al. (2012)</td>
</tr>
<tr>
<td>“Assessment of behavior and psychological problems is essential for both diagnosis and...”</td>
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</table>
management and should be performed in each patient (FPP). Information is gathered from an informant using an appropriate rating scale (e.g. CSDD, GDS, DMAS) (FPP). Although specific BPSD form the core or supportive features of some non-AD dementias, co-morbidity should always be considered as a possible cause (FPP).”  

**Sorbi et al. (2012)**

“… the CSDD [is used] to assess depressive symptomatology …(FPP)” **AQuAs (2010)**

<table>
<thead>
<tr>
<th>fMRI needs further study to determine its utility in Depression in the context of Dementia</th>
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</table>
| “Future studies with large number of participants and longer period of follow-up are needed to allow firm conclusions on the value of fMRI mapping brain activation in various neuropsychiatric and behavioral symptoms in the context of pre-clinical and clinical dementia such as depression, apathy and psychosis, which will help in developing specific treatments for these symptoms (Grade 2C).” **Gauthier et al (2012)**

<table>
<thead>
<tr>
<th>Therapy for Depression in Dementia should include a variety of Non-pharmacologic options.</th>
</tr>
</thead>
</table>
| “For people with dementia who have depression and/or anxiety, cognitive behavioral therapy, which may involve the active participation of their carers, may be considered as part of treatment.” **NICE (2011)**
| “A range of tailored interventions, such as reminiscence therapy, multi-sensory stimulation, animal-assisted therapy and exercise, should be available for people with dementia who have depression and/or anxiety.” **NICE (2011)**
| “The relative simplicity of encouraging patients to increase their daily participation in pleasant activities makes activity scheduling an attractive treatment approach for individuals who may be difficult to treat, such as depressed dementia patients” **Mitchell et al. (2013)**
| “Stimulation-orientated treatment with recreational activities and pleasurable activities has proved to be effective to cope with depression. (Level C)” **AQuAs (2010)**
| “Depressed mood may respond to improvements in the patient’s living situation or to stimulation-oriented treatments [II].” **APA (2010)**

<table>
<thead>
<tr>
<th>Although evidence is mixed, a trial of Anti-depressants could be considered for Depression in Dementia. When choosing an anti-depressant, it is important to consider the anticholinergic side effects.</th>
</tr>
</thead>
</table>
| “People with dementia who also have major depressive disorder should be offered antidepressant medication. Treatment should be started by staff with specialist training, …after a careful risk–benefit assessment. Antidepressant drugs with anti-cholinergic effects should be avoided because they may adversely affect cognition. The need for adherence, time to onset of action and risk of withdrawal effects should be explained at the start of treatment.” **NICE (2011)**
| “If the patient had an inadequate response to the non-pharmacological interventions or has a Major Depressive Disorder, severe dysthymia, or severe emotional liability, we recommend that a trial of an antidepressant could be considered (Grade 2A).” **Gauthier et al (2012)**
| “For depression in dementia, although there is little placebo-controlled evidence to guide practice, clinical experience indicates that SSRIs are safe and effective in treating mood disorders in dementia (Class IV)” **Sorbi et al. (2012)**
| “For depression, there is no RCT demonstrating that anti-depressives do not work in dementia with depression (Grade 5).” **Ihl et al. (2011)**
| “In people with dementia with moderate or severe depression, use of SSRIs may be considered. In case of non-response after at least 3 weeks, they should preferably be referred to a mental health specialist for further assessment and management” **Dua et al. (2011)**

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“SSRIs rather than tricyclic antidepressants should be used to treat depression in AD (Level B).”

**Hort et al. (2010)**

“Antidepressants, preferably sertraline and citalopram may be used in patients with dementia and depression. Tricyclic antidepressants (TCAs) are not recommended due to their adverse effects, despite their similar efficacy. (Level B)”

**AQuAs (2010)**

“[for severe dementia] If necessary, antidepressant drugs, such as SSRIs and TCAs may be used, bearing in mind the possibility of central anticholinergic effects. (Level B)”

“Antidepressants are likely to be efficacious in treatment of depressive symptoms, but they do not improve cognition, and data on antidepressant use in patients with dementia are limited”

**APA (2010)**

“…preference should be given to the SSRIs and TCAs should be avoided because of their anticholinergic effects and resultant concerns about worsening cognition.”

**Gauthier et al (2012)**

“When using antidepressant medications with anticholinergic side effects, it is important to consider the potential for…worsening cognition in individuals with dementia…[I].”

**APA (2010)**

“SSRIs may be preferred because they appear to be better tolerated than other antidepressants [II].”

**APA (2010)**

“Bupropion, venlafaxine, and mirtazapine may also be effective [II].”

**Stimulants can be considered for treatment of Depression in Dementia.**

“…Some patients do well when given stimulants in small doses.”

**APA (2010)**

“[for severe dementia] Psychostimulants such as methylphenidate, dextroamphetamine, modafilin and pemoline may have a fast response and are well-tolerated. Level B”

**AQuAs (2010)**

**Cholinesterase Inhibitors can be considered for treating Dementia-related behaviours, including depression.**

“Treatment with Acetyl Cholinesterase inhibitors is recommended in patients with mild to moderate AD, to manage behavioral alterations (apathy, anxiety and depression), despite the benefit being modest. (Level A)”

**AQuAs (2010)**

**ECT can be considered in certain cases for Depression in those with Dementia.**

“Electroconvulsive therapy is also effective in major depressive disorder superimposed on dementia. It should be used if medications are associated with an excessive risk of adverse effects, are not tolerated, or if immediate resolution of the major depressive disorder episode is medically indicated (such as when it interferes with the patient’s acceptance of food). In individuals with dementia, ECT treatment may be associated with a transient worsening of the patient’s cognitive status”

**APA (2010)**

**Cholinesterase Inhibitors may improved neuropsychiatric symptoms in Lewy Body Disease**

“There is type I evidence to support treatment with cholinesterase inhibitors in Lewy body A dementia, both dementia with Lewy bodies and Parkinson’s disease dementia and that both cognitive and neuropsychiatric symptoms improve.”

**O’Brien et al. 2010**
Appendix E. Focus Group Guide for Physicians

Preamble for Physicians: (Estimated Time: 60 Minutes)

Explanation of Purpose:
Depression and anxiety are very common in patients/persons with neurologic diseases including dementia or Parkinson’s disease. These patients/persons have poor health outcomes, including decreased quality of life, increased mortality or suicide, poor therapy adherence, worsened cognition and decreased functional status. Although we know there are a high number of these patients/persons, they remain under serviced.

As you know, guidelines are intended to summarize the breadth of evidence into evidence-informed recommendations that guide practice. But, despite having guidelines for depression and anxiety among patients/person with dementia or Parkinson’s disease, these patients/persons remain under-diagnosed and under-treated. This represents a gap from evidence to practice. To address this we aim to understand what it is that prevents the use of these guidelines, in order to identify opportunities to improve care for patients.

Explanation of Focus Groups:
Our goal is to assess the understanding of these guidelines and the barriers and facilitators to their use. Today our group is comprised of physicians who are involved in the care of patients with Parkinson’s or Dementia who experience depression or anxiety. You should each have had the summary of findings from the preceding systematic review and discussion guide prior to today. Additionally, you should have reviewed and signed the consent forms prior to this, if not let me know.

I will be aiming to keep us focused through the discussion. We do want you to talk and contribute to the discussion or answer as many questions as you feel able to. It is your right to participate in this group as much or as little as you see fit. You can withdraw from the study at anytime or request that we do not use your contributions.

This discussion will be audio recorded and will be transcribed at a later date. As such please try to allow others to finish before you start. I will do my best to ensure that everyone has a chance to talk if they want to. All information will be stored on password-protected drives. The data will be anonymized to ensure it is non-identifying. The data will all be kept confidential and only
study authors will have access. The final results will be presented in aggregate form only. This study has received ethics approval from the CHREB.

We would like to focus today on patients with dementia or PD that you have seen with depressive or anxiety disorders (depression or anxiety). I have an outline of topics and questions to guide our discussion today. I would like to start broadly with your experiences in diagnosing and managing mood disorders in these patients and then move towards discussing guidelines.

Prior to starting does anyone have any questions? Before starting questions and the audio recording I would like to do introductions around the room.

For the Facilitator: The questions below are meant to relate to the following domains:

Focus Group Questions and Probes for Physicians:

Identification & Diagnosis of Mood Disorders in those with PD or Dementia

1. Tell me about you experiences with diagnosing depressive or anxiety disorders in patients with PD or Dementia?
2. Thinking about your typical patient (with PD or Dementia) with a potential depressive or anxiety disorder, how have they been brought to your attention?
3. What has your experience been with screening tools for depression? Or anxiety?

Additional guiding questions if needed:

a. What were the advantages or disadvantages to using a screening tool?
4. To what extent are others involved in this process? 
E.g. Family, caregivers, other health professionals
5. How was the diagnosis made or what was your diagnostic process?

Additional guiding questions if needed:

a. Have you had experiences in which the availability of time, space, staff or resources affected this process?
6. What skills are necessary to make this diagnosis?

Additional guiding questions if needed:

a. Do you feel it is part of your role to diagnose mood disorders?
7. Who do you feel is the best practitioner to make this diagnosis?

Management of Mood Disorders in those with PD or Dementia
1. Tell me about your experiences with the treatment of depressive or anxiety disorders in patients with PD or Dementia?

2. When considering therapy, which components do you consider? How do you discuss these with your patients?

3. In your practice, do you feel comfortable with the initiation of a treatment plan?

Additional guiding questions if needed:
   a. What enables/prevents you from making treatment plan?
   b. What components do you include in this plan?
   c. What skills do you use in the creation of this plan?

4. What has your experience been with non-pharmacologic management?

   Additional guiding questions if needed:
   a. What types of therapy do you employ here?
   b. What difficulties have you encountered?

5. What has your experience been when pharmacologic therapy is considered?

   Additional guiding questions if needed:
   a. What helps you to initiate therapy for these patients?
   b. Who do you collaborate with to make this decision?
   c. What are the difficulties encountered or barriers to prescribing therapy?

6. In your opinion what is the ideal situation for the management of mood disorders in dementia and PD?

**Experience with Guidelines**

1. Describe your experience with the guidelines that apply to dementia or PD patients that focus on the diagnosis and management of depressive or anxiety disorders?

2. Which guidelines have you used in your practice? (e.g. year, country or organization)

3. How do you use these guidelines in your clinical practice?
   a. Are they helpful? Are they a hindrance?

4. What would help to improve the use of guidelines in your practice?
Appendix F. Focus Group Guide for Patients/Caregivers

Preamble for Patients & Caregivers: (Estimated Time: 60 Minutes)

Explanation of Purpose:
Depression and anxiety are very common in patients/persons with neurologic diseases including dementia or Parkinson’s disease. These patients/persons have poor health outcomes, including decreased quality of life, increased risk of death or suicide, difficulties taking their pills, worsened memory and decreased ability to do the day-to-day tasks.

In medical practice, we have tools called guidelines, which are intended to summarize the scientific evidence into a list of the best recommendations that guide clinical practice. But, despite having guidelines for these disorders among patients/person with dementia or Parkinson’s disease, these patients/persons often remain under-diagnosed and under-treated. This represents a gap between scientific evidence and clinical practices. To address this we aim to understand what it is that prevents the use of these guidelines, in order to identify opportunities to improve care for patients.

Explanation of Focus Groups:
Our goal is to assess the understanding of these guidelines and the barriers and facilitators to their use. Today our group is comprised of patients/caregivers who (have)/(are caregivers of people with) Parkinson’s or Dementia and who experience depression or anxiety. You should each have had the summary of findings from the preceding review of evidence and discussion guide prior to today. Additionally, you should have reviewed and signed the consent forms prior to this, if not let me know.

I will be aiming to keep us focused through the discussion. We do want you to talk and contribute to the discussion or answer as many questions as you feel able to. It is your right to participate in this group as much or as little as you see fit. You can withdraw from the study at anytime or request that we do not use your contributions.

This discussion will be audio recorded and will be transcribed at a later date. As such please try to allow others to finish before you start. I will do my best to ensure that everyone has a chance to talk if they want to. All information will be stored on password-protected drives. The data will be anonymized to ensure it is non-identifying. The data will all be kept confidential and only...
study authors will have access. The final results will be presented in combined form only. This study has received ethics approval from the local ethics review board.

We would like to focus today on your experience with dementia or PD and depression or anxiety. If possible please refer to any health care practitioner by their role (e.g. family doctor, Parkinson’s doctor) and not their names –this is because we seek to examine overall experiences and not directly compare provider practices. I have an outline of topics and questions to guide our discussion today. I would like to start broadly with your experiences in receiving a diagnosis or therapy for depressive or anxiety disorders and then move towards discussing guidelines. Prior to starting does anyone have any questions? Before starting questions and the audio recording I would like to do introductions around the room.

For the Facilitator: The questions below are meant to relate to the following domains:

Focus Group Questions and Probes for Patients & Caregivers:

Identification & Diagnosis of Depression or Anxiety in those with PD or Dementia

1. Thinking about the time before your diagnosis with depression or anxiety, tell me about the symptoms you or others noticed that raised the concern?
2. What was the process you and/or your family went through to get a diagnosis?

Additional guiding questions if needed:
   a. How long did it take before you considered seeking help?
   b. What barriers were there to you obtaining help?
   c. To what extent were other individuals involved in this process?

3. When you were ready to discuss these concerns, which health care provider (HCPs) did you go to? Why?
4. When visiting your HCP how was the concern raised?

Additional guiding questions if needed:
   a. What enabled you to share these concerns with the HCP?

5. As part of this process sometimes HCPs use screening tools (i.e. questions that are meant to help make a diagnosis), have you had any experience with these tools?

Additional guiding questions if needed:
   a. What were the advantages or disadvantages to using a screening tool?
6. Sometimes HCP refer onto specialists –what was your experience with the referral?
Additional guiding questions if needed:

a. Over what time period did the referral take place?

b. What made this process/plan clear or unclear?

7. Tell me now about the experience you had in receiving this diagnosis?

Additional guiding questions if needed:

a. How was it discussed?

b. What made you feel comfortable/uncomfortable in this conversation?

c. Do you feel you received enough information?

d. Who do you feel is the best practitioner to make this diagnosis?

Management of Depressive or Anxiety Disorders in those with PD or Dementia

Now thinking about your experience once you received the diagnosis,

1. Tell me about you experiences with the treatment?

2. What was your experience around the plans for treatment?
   a. When did the discussions about therapy happen?
   b. Who was present for this discussion?
   c. Was it clear what the plan was and how it would be followed up?

3. What type of therapies did you receive? E.g. Counselling, group therapy/sessions, medication etc.
   a. What difficulties have you encountered?
   b. What helps you to initiate therapy for these patients?
   c. What are the difficulties encountered or barriers to getting therapy?

4. During this process were there any difficulties that prevented you from obtaining therapy?

5. In your opinion what is the ideal situation for the management of depression or anxiety in dementia and PD?

6. Reflecting on this process –What parts worked well? Which didn’t?
Appendix G. Focus Group Guide Mapped to Theoretical Domains Framework

Identification & Diagnosis of Mood Disorders in those with PD or Dementia

Skills
Knowledge
Professional Role
Skills
Social Influences
Goals
Knowledge
Beliefs about Capabilities
Memory, Attention,
Decision Process
Intentions
Optimism
Reinforcement
Behavioural Regulation
Beliefs about Consequences
Optimism
Environment
Knowledge
Memory, Attention,
Decision Process
Skills
Knowledge
Goals
Beliefs about Capabilities
Environment
Intentions
Skills
Knowledge
Beliefs about Capabilities
Professional Role
Emotion
Knowledge
Reinforcement
Beliefs about Capabilities
Beliefs about Consequences
Professional Role
Behavioural Regulation
Social Influences
Skills

Tell me about your experiences with diagnosing depressive or anxiety disorders in patients with PD or Dementia?

Thinking about your typical patient (with PD or Dementia) with a potential depressive or anxiety disorder, how have they been brought to your attention?

What has your experience been with screening tools for depression? Or anxiety?

What were the advantages or disadvantages to using a screening tool?

To what extent are others involved in this process?

How was the diagnosis made or what was your diagnostic process?

Have you had experiences in which the availability of time, space, staff or resources affected this process?

What skills are necessary to make this diagnosis?

Do you feel it is part of your role to diagnose mood disorders?

Who do you feel is the best practitioner to make this diagnosis?

Management of Mood Disorders in those with PD or Dementia

Skills
Knowledge
Professional Role

Tell me about your experiences with the treatment of depressive or anxiety disorders in patients with PD or Dementia?
Social Influences
Knowledge
Skills
Beliefs about Capabilities
Optimism
Beliefs about Consequences
Intentions
Goals
Knowledge
Memory, Attention,
Decision Process
Environment
Social Influences
Emotion
Professional Role
Beliefs about Capabilities
Optimism
Intentions
Social Influences
Behavioural Regulation
Knowledge
Environment
Beliefs about Consequences
Beliefs about Capabilities
Memory, Attention,
Decision Process
Knowledge
Beliefs about Consequences
Knowledge
Memory, Attention,
Decision Process
Environment
Skills
Beliefs about Capabilities
Social Influences
Knowledge
Skills
Beliefs about Consequences
Optimism
Environment
Knowledge
Memory, Attention,
Decision Process
Knowledge
Skills
Professional Role

When considering therapy, which components do you consider?
How do you discuss these with your patients?

In your practice, do you feel comfortable with the initiation of a treatment plan?

What enables/prevents you from making treatment plan?

What components do you include in this plan?

What skills do you use in the creation of this plan?

What has your experience been with non-pharmacologic management?

What types of therapy do you employ here?

What difficulties have you encountered?
Beliefs about Capabilities
Beliefs about Consequences
Environment
Social Influences
Knowledge
Skills
Knowledge
Skills
Professional Role
Beliefs about Capabilities
Beliefs about Consequences
Environment
Memory, Attention,
Decision Process
Professional Role
Social Influences
Environment
Memory, Attention,
Decision Process
Social Influences
Professional Role
Social Influences
Emotion
Behavioural Regulation

**Experience with Guidelines**

Skills
Beliefs about Capabilities
Goals
Social Influences
Knowledge
Memory, Attention,
Decision Process
Knowledge
Professional Role
Intentions
Memory, Attention,
Decision Process
Beliefs about Consequences
Environment
Memory, Attention,
Decision Process
Beliefs about Consequences
Goals
Environment
Behavioural Regulation

What has your experience been when pharmacologic therapy is considered?
What helps you to initiate therapy for these patients?

Who do you collaborate with to make this decision?

What are the difficulties encountered or barriers to prescribing therapy?

In your opinion what is the ideal situation for the management of mood disorders in dementia and PD?

Describe your experience with the guidelines that apply to dementia or PD patients that focus on the diagnosis and management of depressive or anxiety disorders?

Which guidelines have you used in your practice?

How do you use these guidelines in your clinical practice?

Are they helpful? Are they a hindrance?

What would help to improve the use of guidelines in your practice?
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<tr>
<td>Sent: July 12, 2016 8:30 AM</td>
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<tr>
<td>To: Zahra Goodarzi</td>
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<tr>
<td>Dear Zahra,</td>
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<td>Sincerely, Bria</td>
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<td>Sent: July 12, 2016 8:42 AM</td>
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<tr>
<td>Regards,</td>
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<tr>
<td>Nathalie</td>
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