Consensus Statement on
Chronic Disease and
Psychological Distress
Effects, diagnosis, prevention and treatment

The Assessment of the Determinants and Epidemiology of
Psychological Distress (ADEPD) Study

The University of Adelaide
Discipline of Psychiatry
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Introduction

► What is a Consensus Development Session?

Consensus development is a process where experts and professionals evaluate the available scientific information on specific issues, resulting in a consensus statement. The process aims to provide an unbiased, independent assessment of health and medical issues and develop a statement that advances understanding of the issue that will be useful to health professionals and the public.

A panel, consisting of an independent group with appropriate expertise, is established. A small number of questions are presented to the panel and after consideration of the data and literature, a workshop is held and a consensus statement is usually developed.
Consensus Statement on Chronic Disease and Psychological Distress

► Background

The Assessment of the Determinants and Epidemiology of Psychological Distress (ADEPD) Study was established to provide information about the relationship between psychological distress and a range of demographic, social, economic, and health-related characteristics in the South Australian population.

The objectives of the ADEPD study are to

- Investigate the relationship between psychological distress (PD)/wellness and socio-economic variables, health indicators, mental health, usage of health service and other mental health instruments
- Develop consensus among experts about determinants of psychological distress
- Provide implications of findings for policies and strategies to reduce psychological distress.

In relation to the second objective, findings from a consensus development session about determinants of psychological distress and its relationship with chronic conditions, is outlined in this document. Other Consensus Development sessions are planned which will enable an overall consensus statement on psychological distress to be developed.

► Process

In the context of the ADEPD Study, health professionals and academics with expertise related to chronic conditions were invited to a consensus development session, which was held in Adelaide, South Australia at the Waverley House Boardroom, St. Andrew's Hospital, 360 South Tce, Adelaide SA 5000 on Saturday, 15th November 2008 from 9am to 12pm.

A definition of psychological distress and the short report “Chronic conditions and Psychological Distress in South Australia: Summary of Results” served as a stimulus to participant discussions and are included with this document.

Questions related to psychological distress and chronic conditions were developed as a basis for discussion at the consensus development session. This report summarises responses to these questions. Verbatim quotes have been chosen to provide supporting examples of issues that were discussed.
Participants

Consensus Development Session Members

Jenny Bennett, Education Services Manager, Arthritis SA

Adrian Booth, Chief Project Officer, Mental Health, Mental Health Promotion Branch, SA Health

Kay Gallary, Programs Manager, Adelaide Central Eastern (ACE) Division of General Practice

Prof Robert Goldney, Assoc. Investigator, ADEPD study, Professor of Psychiatry, University of Adelaide, Director of Psychiatry, RAH

Wendy Keech, Director of Cardiovascular Health, Heart Foundation SA

Joan Lynch, Osteoporosis SA Coordinator, Arthritis and Osteoporosis SA

Dr Pat Phillips, Director Endocrinology, The Queen Elizabeth Hospital

Prof Richard Ruffin, Professor of Medicine, University of Adelaide

Dr Geoff Schrader, Psychiatrist, The Queen Elizabeth Hospital, University of Adelaide

ADEPD Operations Group Members

Prof Helen Winefield, Professor of Psychology, Discipline of Psychiatry, University of Adelaide, ADEPD study

Assoc Prof Anne Taylor, Manager, Population Research and Outcome Studies (PROS) Unit, ADEPD study

Catherine Chittleborough, University of Adelaide, PROS Unit, ADEPD study

Dr Tiffany Gill, Senior Epidemiologist, PROS Unit, ADEPD study

Carmen Koster, Senior Research Officer, University of Adelaide, PROS Unit, ADEPD study

Leanne Hornibrook, Administrative Officer, University of Adelaide, PROS Unit, ADEPD study

Facilitator

Jackie Dakin, Organisational Psychologist, Managing Director of Halifax House Consulting
Consensus Development Questions

ADEPD Operations Group Members developed the following questions for the consensus development session.

1) **How common is psychological distress in your community/patients?**
   What are the current prevalence and patterns of psychological distress for people with chronic conditions in your area of expertise?

2) **What are the effects of psychological distress for your patients/client groups/community?**
   In what ways do you think psychological distress impacts on those with a chronic condition?

3) **How can psychological distress be diagnosed?**
   Can psychological distress be easily recognised? How do you recognise psychological distress? How can psychological distress be diagnosed? Is the Kessler-10 measure appropriate?

4) **How can psychological distress be prevented?**
   Are community based interventions appropriate? What policies and interventions could be put in place to reduce psychological stress? Would these policies fit in the State Strategic Plan/attract government resources?

5) **How can psychological distress be treated?**
   How should it be treated? Is it more appropriate for community based or individual treatments? What policies and interventions could be put in place to reduce psychological stress? Would these policies fit in the State Strategic Plan/attract government resources?

6) **What further research is needed in this field?**
   What are the priorities for future research? Where are the knowledge gaps? What research is needed to make the most progress and greatest population gain? Should the K10 be used for future research?
Definition of Psychological Distress

A working definition of psychological distress was distributed to participants as a hard copy before commencement of the discussion to ensure that participants based their discussion on the same understanding of psychological distress.

A brief summary is given in the following paragraphs with the full definition listed in Appendix 1.

*Psychological distress can be measured using the Kessler 10 Psychological Distress Scale (K10). The K10 was developed to provide a valid, yet brief measure of anxiety and depressive disorders in the general population. The K10 determines the level of psychological distress using a 10 question scale of non-specific psychological distress.

The instrument assesses the level of current anxiety and depressive symptoms experienced by the individual in the month leading up to interview and has been used in a number of Australian population health surveys: the Australian National Mental Health Survey\(^1\); the Collaborative Health and Wellbeing Survey\(^2\); the 1997 and 1998 NSW Health Surveys\(^3\); the Victorian Population Health Surveys\(^4,5\); as well as 2001 National Health Survey\(^6\), using various methods of scoring.*
Question 1: How common is psychological distress in your community/patients?

What are the current prevalence and patterns of psychological distress for people with chronic conditions in your area of expertise?

The discussion on these questions focussed on the following aspects:

- Psychological distress appears to be high in patients with chronic conditions.

- Stage, type and severity of chronic disease, age, effect of peer groups and individual coping mechanisms seem to have an impact on the level of psychological distress as well as subjective measures e.g. individual perception and childhood experiences with repeated behaviour patterns and specific meanings towards environment and life events.

- Younger people with chronic disease are more likely to report psychological distress than older people with a chronic disease.

- Having to cope with a chronic condition might lead to life changes, such as dependency on others, loss of income, which can cause feelings of loss and reduced self-esteem. Psychological distress commonly occurs with life changes and may also occur where the management of a chronic condition fails.

Quotes:

‘...There are high levels of distress when diagnosed with arthritis; loss of independence, mobility, stress with coping with medication…’

‘...It’s an issue of control, when to activate your action plan...’

‘... Are you a lesser person? You lose your freedom, self esteem...’

‘... With diabetes there are issues of burnout. People are so tired of giving injections four times injections a day, everyday and checking blood sugar levels by pricking fingers. And when diagnosed as a young person you also have to deal with adolescence, peer pressure and marriage and children. And you have to learn to live with this burnout...’

CONSENSUS

- Different factors contribute to distress.

- Psychological distress is common but perhaps not recognised enough.

- Psychological distress is affected but not determined by severity of the chronic disease.

- Having a chronic disease affects many other aspects of life that may influence psychological distress.
Question 2: What are the effects of psychological distress for your patients/client groups/community?

In what ways do you think psychological distress impacts on those with a chronic condition?

The discussion on these questions focussed on the following aspects:

- While some people with chronic conditions are able to cope and accept their illness, others are not. This differs between individuals and within individuals over time.

- Ability to cope with chronic conditions, and PD, may be affected by inhibition, learned helplessness/lack of control, the feeling of creating a burden, labelling oneself as a failure or current living conditions.

- People have a limited set of resources. Having a chronic disease takes away some of these resources.

- If one manages the chronic condition, one feels empowered; if one fails to manage, one feels disempowered.

- Loss of self esteem and for some conditions, mortality and loss body image may result.

- The impact on the family is an important issue.

Quotes:

‘...Psychologists once talked about limited resources. We all have a set amount of “oranges” we have to deal with life. Then along comes diabetes or arthritis and it takes away some oranges, some people don’t have any oranges left to deal with life, so they can’t cope and others have enough oranges left to cope. That’s the capacity side of it and it’s important...’

‘...Often people don’t want to disclose pain, suffering, debilitation and the seriousness of the chronic condition to family...’

‘... The message is “you are in control of the condition” and are empowered to manage. However, they [people] try and can’t get it right and feel disempowered and it all leads to learned helplessness...’

Consensus

- People are affected differently by chronic conditions differently.

- Differences vary by social, cultural and economic capital.

- Psychological distress may affect the capacity to care/provide for family and/or loved ones.
**Question 3: How can psychological distress be diagnosed?**

Can psychological distress be easily recognised? How do you recognise psychological distress? How can psychological distress be diagnosed? Is the Kessler-10 measure appropriate?

The discussion on these questions focussed on the following aspects:

- Psychological distress can be assessed, but not diagnosed as it is not classified as an illness.

- K10 and SF36 are utilised as population measures and might also be suited to measure psychological distress for individuals although a shorter scale would be an advantage. The development of a scale measuring resilience/happiness could be an alternative.

- The measures that are utilised as population measures might also be suited to measure psychological distress for individuals, although a shorter scale would be of advantage. The development of a scale measuring resilience/happiness could be an alternative.

- Measurement scales could be utilised by health professionals, mainly general practitioners. However, it is of concern whether interest, time and communication skills of health practitioners allow for the application of such measures.

- A shorter measure could be represented by the following three questions:
  a. Are you feeling depressed?
  b. Have you lost interest in usual activities?
  c. Do you want to do anything about it?

- Patients are often unaware of the relationship between chronic disease and psychological distress. Changes to policies and promotional content could help to educate patients and health professionals.

**Quotes:**

‘...General practitioners do a lot about the physical management of illness but not psychological distress...’

‘...People ring and don’t automatically put two things together e.g. arthritis and psychological distress...’

‘... Nurses could educate patients and forward information .....’

**CONSENSUS**

- Chronic disease and psychological distress are not necessarily linked. A relationship between both needs to be recognised within the broader community as targeting and prevention are important.
• Appropriate balance of time and communication between health professionals and persons with chronic disease and psychological distress is needed. It is also important that health professionals as well as patients are willing to take some action on it.
Question 4: How can psychological distress be prevented?

Are community based interventions appropriate? What policies and interventions could be put in place to reduce psychological stress? Would these policies fit in the State Strategic Plan/attract government resources?

The discussion on these questions focussed on the following aspects:

➢ There should be an emphasis on preventing the onset of chronic conditions and/or psychological distress. Campaigns, including educational curriculum activities, could be utilised to raise public awareness about psychological distress and resilience. These suggestions should be supported within the strategic plan.

➢ Evidence suggests that promotion of physical activity and promotion/presence of counselling helplines e.g. Quitline, are beneficial in improving psychological wellness.

➢ The content of promotions and advertising might be related to the way people perceive and cope with their chronic condition. Funding is usually given for negative content rather than positive. It should be considered whether the promotion of positive content is an option.

Quotes:

‘...We need something like “The body owner’s manual”...’

‘...For funding the negative side should be promoted, but then a positive message should go out to those with a chronic condition...’

‘...Give people more resources e.g. jobs, clothes, in absence of those, we are struggling...’

CONSENSUS

• It is important to provide/promote positive messages regarding resilience, well-being and life skills.

• An appropriate expectation should be associated with disease diagnosis.

• It is important to provide appropriate resources to deal with chronic conditions such as school based prevention programs and essential basic resources such as jobs, housing and transport.

• Connecting with others, being active, taking notice of surroundings, brain stimulation/knowledge and altruistic orientation/behaviour might help prevention.
Question 5: How can psychological distress be treated?

How should it be treated? Is it more appropriate for community based or individual treatments? What policies and interventions could be put in place to reduce psychological stress? Would these policies fit in the State Strategic Plan/attract government resources?

The discussion on these questions focussed on the following aspects:

- Positive messages, such as ‘moving towards wellness’, and interventions are important in developing a sense of belonging, being active, self-help etc.
- Psychological well-being should be promoted rather than psychological distress e.g. wellness promotion in hospitals.
- The problem of this approach is that there is a small proportion of patients who require immediate help e.g. patients with severe mental health disorders.
- Health professionals require more training in diagnosis and community groups require more training, in when to refer to specialists.

Quotes:

‘...Maybe we should not treat psychological distress, but promote well-being...’
‘... Push well-being, but we need programs to identify the 2% [with severe mental health disorders], which are left out of the broad brush approach...’

CONSENSUS

- The focus should be on intervention rather than treatment.
- Concentrate on positives not negatives (well-being not psychological distress) such as with slogans like “Moving towards wellness”.
- Connecting with others, being active, taking notice of surroundings, brain stimulation/knowledge and altruistic orientation/behaviour might help prevention.
Question 6: What further research is needed in this field?

What are the priorities for future research? Where are the knowledge gaps? What research is needed to make the most progress and greatest population gain? Should the K10 be used for future research?

The discussion on these questions focussed on the following aspects:

- It is important to identify why some people are resilient and others are severely stressed.
- Research into genetics and environmental impact would be useful and is currently being undertaken.
- Kessler 10 could be used in future research, but should also integrate a qualitative approach.
- A Kessler 10 or similar scale should be developed to measure psychological distress in children.
- Research questions of interest could be:
  - What are the characteristics of those with low social/economic capital but low psychological distress?
  - What are the characteristics of those with a chronic disease but low psychological distress?
  - How important are happiness, transport, social functioning, and resilience/capacity?

Quotes:

‘... Why are some people severely distressed and certain people are so resilient under the same circumstances?...’

‘...Identify people with immunity...’

CONSENSUS

- Research should utilise both quantitative and qualitative research and focus on why some people cope better than others.
Summary

The consensus development session involving health professionals and academics in the field of chronic disease held on 15 November 2008 with the topic chronic disease and psychological distress achieved the following outcomes:

1) How common is psychological distress in your community/patients?
   - Different factors contribute to distress.
   - Psychological distress is common but perhaps not recognised enough.
   - Psychological distress is affected by severity of the chronic disease.
   - Having a chronic disease affects many other aspects of life in addition to/as well as psychological distress.

2) What are the effects of psychological distress for your patients/client groups/community?
   - Different people are affected differently.
   - Differences varied by social, cultural and economic capital.
   - Psychological distress may affect the capacity to care/provide for family and/or loved ones.

3) How can psychological distress be diagnosed?
   - Chronic disease and psychological distress are talked about in the same domain which is very positive. A relationship between both needs to be recognised within the broader community as targeting and prevention are important.
   - Appropriate balance of time and communication between health professionals and persons with chronic disease and psychological distress is needed. It is also important that health professionals as well as patients are willing to take some action on it.
4) How can psychological distress be prevented?
• It is important to provide/promote positive messages regarding resilience, well-being and life skills.
• An appropriate expectation should be associated with disease diagnosis.
• It is important to provide appropriate resources such as school based prevention programs.
• Connecting with others, being active, taking notice of surroundings, brain stimulation/knowledge and altruistic orientation/behaviour might help prevention.

5) How can psychological distress be treated?
• The focus should be on intervention rather than treatment.
• Concentrate on positives not negatives (well-being not psychological distress) such as slogan like “Moving towards wellness”.
• Connecting with others, being active, taking notice of surroundings, brain stimulation/knowledge and altruistic orientation/behaviour might help prevention.

6) What further research is needed in this field?
• Research should utilise both quantitative and qualitative research and focus on why some people cope better than others.
Based on discussions held the following is the agreed consensus statement on this issue:

CONSENSUS STATEMENT

People with chronic disease have psychological distress but the relationship is often not recognised.

The relationship needs to have a higher profile so that appropriate targeting and prevention can be implemented.

It is important to provide appropriate resources which promote positive messages regarding resilience and well-being as life skills.

Further research should utilise quantitative and qualitative research and focus on why some people cope better than others.
Acknowledgement

We thank all participants for their contribution to this consensus development process. We would also like to acknowledge Jackie Dakin’s involvement as the facilitator and Rosie Bonnin’s contribution in coordinating the planning for the forum. We hope this document will enable better care for those who are affected by chronic disease and/or psychological distress.
APPENDIX 1

ADEPD Study – What do we mean by Psychological Distress?

South Australia’s Strategic Plan ‘Creating Opportunity’ involves selecting a number of quantifiable indicators to measure and track the state’s economic, social and environmental health, creating targets for improvement. The second major objective of the Plan is ‘Improving Wellbeing’. One target considered under this objective is to address psychological distress in South Australia, bringing it to a level equal or lower than the Australian average within 10 years.

Psychological distress can be measured using the Kessler 10 Psychological Distress Scale (K10). The K10 was developed in 1992 for use in the redesigned United States National Health Interview Survey (US-NHIS). The instrument assesses the level of current anxiety and depressive symptoms experienced by the individual in the month leading up to interview and has been used in a number of Australian population health surveys: the Australian National Mental Health Survey\(^1\); the Collaborative Health and Wellbeing Survey\(^2\); the 1997 and 1998 NSW Health Surveys\(^3\); the Victorian Population Health Surveys\(^4,5\); as well as 2001 National Health Survey\(^6\), using various methods of scoring.

The K10 was developed to provide a valid, yet brief measure of anxiety and depressive disorders in the general population. The K10 determines the level of psychological distress using a 10 question scale of non-specific psychological distress. The items are based on the level of anxiety and depressive symptoms experienced in the most recent four week period, and allow subjects to report the frequency of each experience on the following scale:

1) None of the time
2) A little of the time
3) Some of the time
4) Most of the time
5) All of the time

The questions used in K10 are:

1) In the past four weeks, about how often did you feel tired out for no good reason?
2) In the past four weeks, about how often did you feel nervous?
3) In the past four weeks, about how often did you feel so nervous that nothing could calm you down?
4) In the past four weeks, about how often did you feel restless or fidgety?
5) In the past four weeks, about how often did you feel so restless you could not sit still?
6) In the past four weeks, about how often did you feel depressed?
7) In the past four weeks, about how often did you feel everything was an effort?
8) In the past four weeks, about how often did you feel worthless?
The values of the response categories are reversed so that: 5 is “all of the time”, and 1 is “none of the time”. The 10 items are summed to give scores ranging from 10 and 50, where a sum of 50 indicates a high risk of anxiety or a depressive disorder.

The table below presents the cut-off scores for the level of risk of anxiety or a depressive disorder.

### K10 Psychological Distress Status Cut-off Scores

<table>
<thead>
<tr>
<th>K10 Score</th>
<th>Level of Psychological Distress</th>
<th>Level of Psychological Distress</th>
</tr>
</thead>
<tbody>
<tr>
<td>10-15</td>
<td>Low</td>
<td>No Psychological Distress</td>
</tr>
<tr>
<td>16-21</td>
<td>Moderate</td>
<td></td>
</tr>
<tr>
<td>22-29</td>
<td>High</td>
<td>Psychological Distress</td>
</tr>
<tr>
<td>30-50</td>
<td>Very High</td>
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### REFERENCES


