

**Institution:** The Open University

**Unit of Assessment:** A3, Allied Health Professions, Dentistry, Nursing and Pharmacy

**Title of case study:** Psychosocial factors and impact on knowledge and understanding about diabetes care

### 1. Summary of the impact

Dr Lloyd's research examines the relationship between diabetes and mental health, particularly in under-served or marginalised communities. Through extensive international collaborations research findings have been disseminated to a wide audience. Locally, service users have been involved in the development of alternative ways of obtaining informed consent, to allow greater research inclusivity. Culturally appropriate tools, for identifying depressive symptoms as well as knowledge deficits in diabetes self-care, have been designed and tested. As a result, a psychotherapy service for people with co-morbid diabetes and psychological problems has been successfully established in a diabetes centre attended by more than 6,000 individuals.

### 2. Underpinning research

Between 1993 - 2013, Open University (OU) academic Dr Lloyd has been leading investigations towards a better understanding of the impact of diabetes on mental health, and developing innovative ways of ensuring greater inclusivity – in particular of minority ethnic groups – in research. Her work crosses disciplinary boundaries, and her collaborative activities include research partnerships between academics (for example Professor Trevor Orchard (University of Pittsburgh), Professor Tom Fitzgerald (University of Michigan)), and a range of health care professionals and service users (including Professor Anthony Barnett (Heart of England NHS Trust and University of Birmingham), Dr Katharine Barnard (University of Southampton), Dr Srikanth Bellary (Diabetes Centre, Heart of England NHS Trust)). Lloyd's two recent books on psychological issues in people with diabetes are both aimed at health care practitioners [3.1, 3.2].

Using qualitative and quantitative methods, Lloyd's research in both the UK and USA has focused on the relationship between diabetes and mental health, for example the important practice implications for distinguishing between symptoms of depression and diabetes-related emotional distress [3.1]. She has concentrated particularly on South Asians with diabetes, a population at increased risk for Type 2 diabetes and who are known to experience poor mental health.

Lloyd's involvement in health services research for people with diabetes has included research into ways of ensuring greater inclusivity and developing culturally applicable survey tools for the substantial (more than 50%) south Asian population attending Birmingham Heartlands Hospital diabetes outpatients clinic. Her work has included the development of alternative ways of securing informed consent from individuals with language or literacy difficulties [3.6]. This has ensured that any person from the Pakistani or Bangladeshi communities living in the Heartlands Hospital catchment area is not excluded from research on the basis of their ethnicity or their language or literacy skills, as audio methods of taking informed consent (developed by Lloyd) are available.

Lloyd has also developed alternative methods of data collection, for use in diabetes populations who are under-served or marginalised. Most notably these methods involved developing culturally adapted questionnaires in both written and audio format. In collaboration with service users and health care professionals, Lloyd has developed culturally appropriate measures of knowledge of, and confidence with, diabetes self-management, including a diabetes knowledge scale, adapted for ease of completion, and now used in a number of other research studies both nationally and internationally. These questionnaires are available in Urdu and Bengali as well as audio versions in Mirpuri and Sylheti, which are spoken (not written) languages used by two of the south Asian

groups living in the UK who are most affected by Type 2 diabetes. Lloyd has also led the cultural adaptation of two commonly used screening tools for identifying symptoms of depression, including the PHQ-9, the most commonly used instrument for measuring depressive symptoms in primary care and recommended for use by the Department of Health Quality Outcomes Framework [3.3, 3.4, 3.5]. These tools can be used as either written or audio questionnaires.

### 3. References to the research

1. Lloyd, C.E., Pouwer, F. and Hermanns, N. (eds) (2012) *Screening for Depression and Other Psychological Problems in Diabetes*, London, Springer, 220pp; ISBN 978-0-85729-750-1.
2. Barnard, K. and Lloyd, C.E. (eds) (2012) *Psychology and Diabetes Care: A Practical Guide*, London, Springer, 177pp; ISBN: 978-0-85729-572-9.
3. Lloyd, C.E. et al. (2012) 'Measuring psychological wellbeing in South Asians with diabetes: a qualitative investigation of the PHQ-9 and the WHO-5 as potential screening tools for measuring symptoms of depression', *Diabetic Medicine*, vol. 29, no. 1, pp. 140–47; DOI: 10.1111/j.1464-5491.2011.03481.x
4. Roy, T., Lloyd, C.E. et al. (2011) 'Screening tools used for measuring depression among people with Type 1 and Type 2 diabetes: a systematic review', *Diabetic Medicine*, vol. 29, no 2, pp. 164–75; DOI: 10.1111/j.1464-5491.2011.03401.x
5. Lloyd, C.E., Sturt, J., Johnson, M.R.D., Mughal, S., Collins, G. and Barnett, A.H. (2008) 'Development of alternative modes of data collection in South Asians with Type 2 diabetes', *Diabetic Medicine*, vol. 25, no. 4, pp. 455–6; DOI: 10.1111/j.1464-5491.2008.02401.x
6. Lloyd, C.E., Johnson, M.R.D., Mughal, S., Sturt, J.A., Collins, G.S., Roy, T., Bibi, R. and Barnett, A.H. (2008) 'Securing recruitment and obtaining informed consent in minority ethnic groups in the UK', *BMC Health Services Research*, vol. 8, pp. 68–76; doi:10.1186/1472-6963-8-68

### Grants

2013–15: £25,070 (total project worth £800,000) awarded by the Association for the Improvement of Mental Health Programmes to C.E. Lloyd for a project entitled 'International Prevalence and Treatment of Diabetes and Depression'. PI: CE Lloyd

2010–12: £14,735 awarded by Diabetes UK to C.E. Lloyd for a project entitled 'Identifying psychological problems in South Asians with Diabetes'. PI: CE Lloyd

2007–10: £93,499 awarded by Diabetes UK to K. Matyka, University of Warwick (Co-I: C.E. Lloyd) project entitled 'Fear of hypoglycaemia in childhood diabetes'. Co-I: CE Lloyd

2007–09: £12,842 awarded by Pfizer Ltd to C.E. Lloyd for a project entitled 'Perceptions of insulin treatment in people with Type 2 diabetes: a comparison between adults from South Asian backgrounds and UK white Caucasians'.

2006–08: £50,000 awarded by MRC to J. Sturt, University of Warwick (Co-I: C.E. Lloyd) for a project entitled 'The development of a protocol to assess self-efficacy and knowledge in negotiating goals in diabetes'.

2006–07: £9,045 awarded by Novo Nordisk to C.E. Lloyd for a project entitled 'Development of alternative methods of data collection: perceptions of care in south Asians with Type 2 diabetes'.

2005–07: £29,554 awarded by Diabetes UK to C.E. Lloyd for a project entitled 'The development of alternative modes of data collection in minority ethnic populations with diabetes'.

### 4. Details of the impact

Dr Lloyd's research has made an impact on clinical practice through the provision of an improved local psychology service so that more than 6,000 diabetes patients now have access to

psychological care.

The research has also raised awareness of the importance of psychosocial factors in diabetes care both in the UK and internationally through conference presentations and the publication of books and reports (e.g. [http://www.diabetes.org.uk/upload/Reports/South\\_Asian\\_report.pdf](http://www.diabetes.org.uk/upload/Reports/South_Asian_report.pdf)), with clinical researchers and practitioner translating the findings of her research into their own methodologies and clinical studies.

### **Clinical Research impact**

Lloyd's research into the development of questionnaires to measure knowledge of diabetes has led to her questionnaires being used in research studies in Bangladesh, Pakistan, University of Taiwan, University of Kansas, East Carolina University and by clinical psychology PhD students at Trinity College Dublin. As psychologist Professor Fitzgerald (University of Michigan) states, there has been extensive use of Lloyd's diabetes knowledge questionnaires.

Lloyd's research expertise in recruiting and researching the views of south Asians is currently (2012 onwards) playing a significant role in the design and execution of the final two qualitative phases of the national IMPROVE study of GP satisfaction at Cambridge University Primary Care Unit at the Institute of Public Health.

A strong feature of Lloyd's research has been to increase awareness for the need for culturally appropriate survey tools. She has presented her research findings at national and international professional and scientific meetings, and her methods were replicated in a study of diabetes and mental health in Bangladesh and are currently being tested in Pakistan. Her work has informed the design of a new international study on diabetes and depression, the INTERPRET-DD study, supported by the Dialogue on Diabetes and Depression (DDD) ([http://www.diabetesanddepression.org/structure\\_participants.html](http://www.diabetesanddepression.org/structure_participants.html)).

Lloyd has conducted workshops where approximately 45 service users and health care professionals have come together, not only to hear about research in this area but also to test audio methods of gaining consenting to take part in research studies and in completing questionnaires. Service users have also contributed to the presentations given at the workshops and supported the subsequent report writing (e.g. Lloyd, 2010).

Research impact is further demonstrated through three edited books, two written specifically for practitioners [3.1, 3.2]; the publication of new recommendations for research and practice, launched at the House of Lords and Lloyd's contribution to a section of *Diapedia*, a new online textbook of diabetes supported by the European Association for the Study of Diabetes.

Impact is also evidenced by Lloyd's membership of the Editorial Advisory Board for a new diabetes self-management tool.

### **Clinical Practice impact – psychology service**

Lloyd's research has informed clinical practice. Her research into how stressful experiences leads to poorer diabetic control and poorer mental health led to the establishment in 1997 of a new psychology service within the Diabetes Centre, Birmingham Heartlands Hospital, which cares for more than 6,000 patients with diabetes. Lloyd designed a new screening tool to identify patients with diabetes who were having difficulties with their diabetes control and who were also in need of psychological support. She trained the health care professionals within the diabetes clinic to assess patients for depression and anxiety and, if necessary, to refer them to the psychology service. Lloyd's research directly led to her success in obtaining the initial funding for this service from Novo Nordisk (~£15K), prior to direct long-term funding from the Heart of England Hospital Trust at a cost of ~£12k per annum. Lloyd also contributed to a handbook of diabetes care for use by health care practitioners.

### The international impact

The international impact of Lloyd's research is evidenced firstly through her involvement in the Pittsburgh Epidemiology of Diabetes Complications (EDC) Study, an ongoing study into the physical and psychosocial complications of Type 1 diabetes. Lloyd's involvement spans more than 22 years and includes data collection, writing research papers and supervising a PhD student.

International impact is further evidenced by her current research with Dialogue in Diabetes and Depression (DDD), where she chairs the Epidemiology Working Group. Through this initiative Lloyd now leads a new international study bringing together leading psychiatrists and diabetologists as well as academics in 17 countries: Argentina, Brazil, Canada, China, Ethiopia, Germany, India, Italy, Kenya, Kuwait, Mexico, Pakistan, Poland, Russia, Serbia, Thailand, Ukraine.

### Public engagement

Lloyd has led workshops and focus groups for service users with diabetes, for example consultations with women with gestational diabetes, both Type 1 or Type 2 diabetes when designing a new project on diabetes and pregnancy in white Caucasians and south Asians. The findings of her research on knowledge and self-management of diabetes in south Asians were disseminated through a meeting of service users who had participated in the research.

## 5. Sources to corroborate the impact

### Organisations who can corroborate claims of contribution, benefit and impact

Clinical Director, Diabetes Centre, Diabetes Birmingham Heartlands Hospital

**Dialogue on Diabetes and Depression web page:** <http://diabetesanddepression.org/>

### Reports aimed at health-care professionals (launched by the House of Lords)

Gill, P.S. and Lloyd, C.E. (2009) 'Participation in research' in Khunti, K., Kumar, S. and Brodie, J (Eds) *Diabetes UK and South Asian Health Foundation Recommendations on Diabetes Research Priorities for British South Asians*, London, Diabetes UK, ISBN 978-1-899288-88-5.

Stone, M. and Lloyd, C.E. (2009) 'Psychological consequences of diabetes' in Khunti, K., Kumar, S. and Brodie, J (Eds) *Diabetes UK and South Asian Health Foundation Recommendations on Diabetes Research Priorities for British South Asians*, London, Diabetes UK, ISBN 978-1-899288-88-5.

### Public understanding of mental health issues:

#### Aimed at health-care practitioners

Lloyd, C.E. (2012) 'Challenges to good diabetes care' in Barnett, A.H. (Ed.) 2nd edn, *Management of Type 2 Diabetes*, Oxford, Oxford University Press, ISBN 978-0-19-959617-1.

#### Aimed at end-users

Barnett, A.H., Anstiss, T., Ceriello, A., Cradock, S., Hall, G., Lloyd, C.E., del Prato, S., Vora, J. and Wens, J. (Eds) (2011) *My Diabetes, My Choice, My Path; Supportive Self-management in Type 2 Diabetes*, Uxbridge and Paris, Bristol-Meyers Squibb and AstraZeneca.

#### Aimed at the general public

Lloyd, C.E. (2013) 'Depression: screening tools', *Diapedia* [online], [cited 3 April 2013], Diapedia 61047161602 rev. no. 7. Available from:

<http://www.diapedia.org/associateddisorders/61047161602/depression-screening-tools>