

ANA PATRÍCIA HILÁRIO

PERSONAL INFORMATION

Date of birth: 27.03.1982
Nationality: Portuguese
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EDUCATION

September 2008 – February 2015

PhD in Sociology, Royal Holloway, University of London, UK

Thesis Title: 'The body and its shadows: an exploration of the bodily experiences of terminally ill patients', Supervisor: Prof. Jonathan Gabe

October 2006 – July 2007:

Post-graduation in Family and Society, ISCTE-IUL, Portugal, 17 values

October 2000 – July 2006:

Degree in Sociology and Planning (Pre-Bolonha/5 years), ISCTE-IUL, Portugal, 15 values

Thesis Title: 'The Conspiracy of Silence: contributions for a new approach on death and dying in Portugal', Supervisor: Prof. Graça Carapineiro

RESEARCH EXPERIENCE

October 2015 – present:

Research Assistant, Project 'ANED – Academic Network of European Disability Experts', Disability and Human Rights Observatory, ISCSP, Portugal

September 2008 – February 2015:

PhD Candidate in Sociology, Thesis 'The body and its shadows: an exploration of the bodily experiences of terminally ill patients', Royal Holloway/University of London & CIES-ISCTE, United Kingdom & Portugal

December 2007 – August 2008:

Research Assistant, Project 'Medications and therapeutic pluralism: social consumptions, logic(s) and rationalities', CIES/ISCTE-IUL, Portugal

April 2007 – November 2007:

Research Assistant, Project 'Diagnostic and Evaluation of Committee Protection of Children and Young People' CIES/ISCTE-IUL, Portugal

October 2006 – March 2007:

Research Assistant: Project 'European Social Survey', ICS-UL, Portugal

March 2005 – April 2005:

Interviewer, Project 'Evaluation and Security of the Social Responses of Rehabilitation and Integration of Disable People', IESE/CIES, Portugal

June 2003 – August 2003:

Interviewer, Project 'West Immigrants in Portugal: from emigration to integration, CESIS, Portugal'

TEACHING EXPERIENCE

March 2015 – July 2015:

Antropossociology and Field Work, Undergraduate, Piaget Institute, Portugal

October 2009 – February 2010:

General Sociology I, Undergraduate, Open University (e-learning), Portugal

Sociology of Family I, Undergraduate, Open University (e-learning), Portugal

GUEST LECTURES

June 2013:

Ethnographic Research, Graduate, M.A. Palliative Care, Faculty of Medicine of the University of Lisbon, Portugal

May 2012:

Ethnographic Research, Graduate, M.A. Palliative Care, Faculty of Medicine of the University of Lisbon, Portugal

July 2011:

Body, Death and Society, Graduate, M.A. Radiotherapy, Lisbon School of Health Technology, Portugal

May 2011:

Ethnographic Research, Graduate, M.A. Palliative Care, Faculty of Medicine of the University of Lisbon, Portugal

September 2010:

Death and Society, Undergraduate, Degree in Medicine, Faculty of Medicine of the University of Lisbon, Portugal

May 2010:

Ethnographic Research, Graduate, M.A. Palliative Care, Faculty of Medicine of the University of Lisbon, Portugal

OTHER ACADEMIC ACTIVITIES

September 2013 – August 2015:

PhD Representative of the Research Network 16 (Sociology of Health and Illness), the European Sociological Association

September 2011 – August 2015:

Co-Coordinator of the Newsletter of the Research Network 16 (Sociology of Health and Illness), the European Sociological Association

September 2011 – August 2015:

Board Member of the Research Network 16 (Sociology of Health and Illness), the European Sociological Association

ORGANISATION OF SCIENTIFIC MEETINGS

Session ‘Emotions and the Qualitative Health Researcher’, Mid-Term Conference of the Research Network of Sociology of Health and Illness (RN16), European Sociological Association, 19-21 May 2016

Session ‘Listening to the voices of children: how to bring them into the sociology of health and illness’, Mid-Term Conference of the Research Network of Sociology of Health and Illness (RN16), European Sociological Association, 19-21 May 2016

PhD & Early Scholars Workshop ‘Quantitative, qualitative and mixed methods research: new insights for the study of health and illness’, Research Network of Sociology of Health and Illness (RN16), European Sociological Association, 18 May 2016

Session ‘The Impact of Gender, Class and Ethnicity on End of life Experiences’, Research Network of Sociology of Health and Illness (RN16), 12th European Sociological Association Conference, Prague, Czech Technical University, 25-29 August 2015

General Sessions, Research Network of Sociology of Health and Illness (RN16), 12th European Sociological Association Conference, Prague, Czech Technical University, 25-29 August 2015

General Sessions, Research Network of Sociology of Health and Illness (RN16), 11th European Sociological Association Conference, Torino, Torino University, 29 August-1 September 2013

PANEL CHAIR

Session ‘The Politics of Healthcare and Illness Management’, Research Network of Sociology of Health and Illness (RN16), 12th European Sociological Association Conference, Prague, Czech Technical University, 25-29 August 2015

Session ‘Health and Illness in Mediterranean Countries: Present Challenges and Future Developments’, Research Network of Sociology of Health and Illness (RN16), 12th European Sociological Association Conference, Prague, Czech Technical University, 25-29 August 2015

Session ‘Chronic Illness II: Experiences and Recognition’, Research Network of Sociology of Health and Illness (RN16), 11th European Sociological Association Conference, Torino, Torino University, 29 August-1 September 2013

SCIENTIFIC JURY

Ana Catarina Rodrigues Correia, “O meu corpo é público?”: Representações do corpo em contexto de paralisia cerebral, Master Thesis in Sociology supervised by Professora Doutora Alexandra Lopes

PUBLICATIONS

Hilário, A.P. (in press). The Stigma experienced by Terminally Ill Patients: Evidence from a Portuguese Ethnographic Study. *Journal of Social Work in End-of-Life & Palliative Care*,

Hilário, Ana Patrícia (in press) “Witnessing a body in decline: Men’s and women’s perceptions of an altered physical appearance”, *Journal of Woman and Aging*,

Hilário, Ana Patrícia (2016) “In-patient hospice: qualitative study with Portuguese patients, family and staff”, *Death Studies*,

Hilário, Ana Patrícia (2015) “Making sense of a changed physical body: Why gender matters at end of life”, *Journal of Aging Studies*, 33, pp. 58–66.

Hilário, Ana Patrícia (2012), “What about dignity? The meaning and experience of terminally ill patients”, *CIES e-Working Paper N° 122/2012*, Lisboa, CIES, ISCTE-IUL

Hilário, Ana Patrícia (2011) “Understanding dignity at the end of life: the experience of palliative care patients.” In Steele, S. & Caswell, G. (Eds) *Exploring Issues of Care, Dying and the End of Life*. Oxford: Interdisciplinary Press., pg-pg. 123-134

Hilário, Ana Patrícia (2010) “O discurso da boa morte nas vozes de quem cuida.”, *Alicerces: Revista de Investigação, Ciência, Tecnologia e Artes*. Vol. III, N.º 3, Lisboa, Instituto Politécnico de Lisboa

Hilário, Ana Patrícia (2009), “Journeys into end of life research: some methodological considerations”, *CIES e-Working Paper N° 82/2009*, Lisboa, CIES, ISCTE-IUL

Hilário, Ana Patrícia (2009), “The conspiracy of silence: Contributions for a new sociological approach about death and dying.” In E. Morin, N. Ramalho, A. Savoie & J. Neves (Eds). *New research trends in effectiveness, health, and work: A Criteos scientific and professional account*. Montreal: Criteos/HEC-Montreal., pg-pg. 141-156

Hilário, Ana Patrícia (2008) “Enfrentando o fantasma da morte: as estratégias negociadas e as lógicas partilhadas pelos enfermeiros de um serviço de cuidados paliativos”, *VI Congress of the Portuguese Sociological Association*, Lisbon, Universidade Nova de Lisboa

Torres, Analia, Elsa Pegado, Manuel Sarmiento, Ana Patrícia Hilário, Andreia Freitas, Isabel Sousa, Raquel Cruz, Raquel Penha (2009), *Estudo de Diagnóstico e Avaliação das Comissões de Protecção de Crianças e Jovens - Sinopse*, CIES, ISCTE-IUL, Lisboa

Torres, Analia (coord.), Elsa Pegado, Manuel Sarmiento, Ana Patrícia Hilário, Andreia Freitas, Isabel Sousa, Raquel Cruz, Raquel Penha (2008), *Estudo de Diagnóstico e Avaliação das Comissões de Protecção de Crianças e Jovens*. Volume Complementar IV: Dossier de casos mediatizados.

Torres, Analia (coord.), Elsa Pegado, Manuel Sarmiento, Ana Patrícia Hilário, Andreia Freitas, Isabel Sousa, Raquel Cruz, Raquel Penha (2008), *Estudo de Diagnóstico e Avaliação das Comissões de Protecção de Crianças e Jovens*. Volume Complementar III: Relatos de Casos acompanhados pelas CPCJ.

Torres, Analia (coord.), Elsa Pegado, Manuel Sarmiento, Ana Patrícia Hilário, Andreia Freitas, Isabel Sousa, Raquel Cruz, Raquel Penha (2008), *Estudo de Diagnóstico e Avaliação das Comissões de Protecção de Crianças e Jovens*. Volume Complementar II: Sistemas de Protecção de vários países.

Torres, Analia (coord.), Elsa Pegado, Manuel Sarmiento, Ana Patrícia Hilário, Andreia Freitas, Isabel Sousa, Raquel Cruz, Raquel Penha (2008), *Estudo de Diagnóstico e Avaliação das Comissões de Protecção de Crianças e Jovens*. Volume complementar I: Análise dos Relatórios das Actividades das CPCJ.

Torres, Analia (coord.), Elsa Pegado, Ana Patrícia Hilário, Raquel Cruz, Ana Raquel Penha, Andrea Freitas, Isabel Sousa e Manuel Sarmiento (2008), *Estudo de Diagnóstico e Avaliação das Comissões de Protecção de Crianças e Jovens: Relatório Final*, Lisboa (policopiado).

CONFERENCE PRESENTATIONS

Hilário, Ana Patrícia (2015) “Desafios ético-metodológicos na pesquisa qualitativa em Saúde: um olhar a partir de um estudo de caso em torno da temática do fim de vida”, Simpósio Investigação Sociológica em Saúde: questões éticas, Almada, Egas Moniz - Instituto Superior de Ciências da Saúde, 11 December

Hilário, Ana Patrícia (2015) “Men’s and women’s experiences of loss of bodily autonomy at end of life”, 12th European Sociological Association Conference, Prague, Czech Technical University, 25-29 August

Hilário, Ana Patrícia (2013) “Dying patient’s experiences: an exploration of their decaying and deteriorating bodies”, 11th European Sociological Association Conference, Torino, Torino University, 29 August – 1 September

Hilário, Ana Patrícia (2012) “Making Sense of Terminal Illness”, International Conference on Challenges for Health and Health Care in Europe, Aalborg, Aalborg University, 1-2 November

Hilário, Ana Patrícia (2012) “Um olhar sobre a pesquisa etnográfica no final da vida”, V Congresso Ibero-americano de Pesquisa Qualitativa, Lisbon, ISCSP, 11-13 October

Hilário, Ana Patrícia (2012) “Um olhar sobre a dilaceração da identidade no final da vida”, VII Congresso Português de Sociologia, Porto, Faculdade de Letras da Universidade do Porto, 19-22 June

Hilário, Ana Patrícia (2011) “What about dignity: the meaning and experience of terminally ill patients”, 10th European Sociological Association Conference, Geneve, Uni Mail, 7-10 September

Hilário, Ana Patrícia (2011) “Challenges in end of life research: the story of a journey”, 10th European Sociological Association Conference, Geneve, Uni Mail, 7-10 September

Hilário, Ana Patrícia (2011) “The unbounded dying body: stories of terminally ill patients”, PhD Research Day, London, Royal Holloway University of London, 15 June

Hilário, Ana Patrícia (2011) “The body and its shadows: reflections on the unbounded dying body”, BSA Annual Conference 2011, London, London School of Economics, 6-8 April

Hilário, Ana Patrícia (2010) “Understanding dignity at the end of life: the experience of palliative care patients”, 7th Global Conference Making Sense of: Dying and Death, Praha, Michna Palace, 8-10 November

Hilário, Ana Patrícia (2010) “Mirrors and shadows: an exploration of the non-negotiable deteriorating bodies of terminally ill patients”, ISA World Congress of Sociology, Gothenburg, Svenska Massan, 11-14 July

Hilário, Ana Patrícia (2009) "Suffering bodies: an exploration of the missing link between the body and self-identity in the dying process ", 9th European Sociological Association Conference, Lisbon, ISCTE - IUL, 2-5 September

Hilário, Ana Patrícia (2009) “The corporeal realities of dying patients: core reflections”, *The British Sociological Association Annual Conference*, Cardiff, Cardiff City Hall, 16-18 April

Hilário, Ana Patrícia (2008) “Enfrentando o fantasma da morte: as estratégias negociadas e as lógicas partilhadas pelos enfermeiros de um serviço de cuidados paliativos”, *VI Congress of the Portuguese Sociological Association*, Lisbon, Universidade Nova de Lisboa, 25-28 June

Hilário, Ana Patrícia (2008) “O discurso da boa morte nas vozes de quem cuida”, *II Journeys of Human and Social Sciences in Health*, Lisbon, ESTSL, 4-5 April

Hilário, Ana Patrícia (2006) “The conspiracy of silence: contributions for a new sociological approach about death and dying”, *III International Forum Criteos*, Lisbon, ISCTE, 23-25 November

AWARDS

October 2004 – July 2005:

Academic Merit Grant for the undergraduate student of the year in the degree in Sociology and Planning of ISCTE-IUL, Portuguese Ministry of Science, Technology and Higher Education

October 2004 – July 2005:

Academic Merit Prize for the undergraduate student of the year of the Department of Sociology, Presidency of ISCTE/IUL

INTERCHANGE PROGRAMMES

September 2002 – March 2003:

Erasmus Programme, Warwick University, United Kingdom

OTHER COURSES

April 2009:

Basic Course on Palliative Care

National Association on Palliative Care

November 2005:

Course on Sensibility of Equal Opportunities

Comission for Gender Equality

LANGUAGE

English – Very good speaking and writing