

CURRICULUM VITÆ

Ana Patrícia Silva Souto Lourenço Hilário

1. Personal Information

Birth place and date: Lisbon, 27 March 1982

Nationality: Portuguese

Institucional address:

Instituto de Ciências Sociais, Universidade de Lisboa

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2. Summary

Ana Patrícia Hilário has recently been awarded a Research Fellow Position at Instituto de Ciências Sociais, Universidade de Lisboa (ICS-ULisboa) with the project 'Making visible the invisible: an exploration on family experiences and management of chronic pain in childhood', under the Scientific Employment Stimulus 2017 funded by the Portuguese Foundation for Science and Technology (FCT).

Previously, she held a post-doctoral position under the framework of the project TRANSRIGHTS: 'Gender citizenship and sexual rights in Europe: Transgender lives in transnational perspective' funded by the European Research Council (ERC) at ICS-ULisboa. She had been a guest lecturer at Instituto Piaget and at Escola Superior de Saúde, Instituto Politécnico de Santarém. She had also worked as a research assistant at Instituto Universitário de Lisboa, ISCTE-IUL, Instituto Superior de Ciências Sociais e Políticas (ISCSP-ULisboa) and Instituto de Ciências Sociais, Universidade de Lisboa (ICS-ULisboa).

She had organized several scientific national and international events and was published in international journals in the fields of gender, health, ageing and death (Journal of Gender Studies; Journal of Social Theory & Health; Health (London); Journal of Women & Aging; Journal of Aging Studies; Palliative & Supportive Care; Journal of Social Work in End-of-Life & Palliative Care; Death Studies). She had also been a reviewer for leading journals in her field of expertise (Social Theory & Health; Health (London); Health and Social Care in the Community; Death Studies; Palliative Medicine; Interface: Comunicação, Saúde, Educação; Saúde e Sociedade).

She had been a board member of the European Research Network of Sociology of Health and Illness.

Ana Patrícia qualified with a PhD in Medical Sociology at Royal Holloway, University of London, in 2015.

Her current main research interests focus on the Sociology of Health and Illness, Sociology of Diagnosis, Sociology of Gender and Sociology of Childhood and Youth.

3. Education

Years	Academic degree	Course	Institution	Classification
2015	PhD	Sociology	Royal Holloway, University of London	-
2007	Post-graduation	Family and Society	Instituto Universitário de Lisboa, ISCTE-IUL	17/20
2006	Licenciante	Sociology and Planning (Pre- Bolonha)	Instituto Universitário de Lisboa, ISCTE-IUL	15/20

4. Academic Experience

4.1. Research Positions

May 2019	Research Fellow, Project ‘Making visible the invisible: an exploration on family experiences and management of chronic pain in childhood’, Instituto de Ciências Sociais, Universidade de Lisboa, Portugal, Funded by the Portuguese Foundation for Science and Technology (FCT) under the Scientific Employment Stimulus 2017.
April 2016 - April 2019	Postdoctoral Researcher, Project ‘TRANSRIGHTS - Gender citizenship and sexual rights in Europe: Transgender lives from a transnational perspective’, Instituto de Ciências Sociais, Universidade de Lisboa, Portugal, Funded by the European Research Council under the European Union's Seventh Framework Programme (FP7/2007-2013) / ERC grant agreement n° 615594.
October 2015 - March 2016	Research Assistant, Project ‘ANED - Academic Network of European Disability Experts’, Instituto Superior de Ciências Sociais e Políticas, Universidade de Lisboa, Portugal.
September 2008 - October 2014	PhD Researcher, Project ‘The body and its shadows: an exploration of the bodily experiences of terminally ill patients’, Centro de Investigação e Estudos em Sociologia, Instituto Universitário de Lisboa, ISCTE-IUL, Portugal.

December 2007 - August 2008	Research Assistant, Project ‘Medications and therapeutic pluralism: social consumptions, logic(s) and rationalities’, Centro de Investigação e Estudos em Sociologia, Instituto Universitário de Lisboa, ISCTE-IUL, Portugal.
April 2007 - November 2007	Research Assistant, Project ‘Diagnostic and Evaluation of Committee Protection of Children and Young People’, Centro de Investigação e Estudos em Sociologia, Instituto Universitário de Lisboa, ISCTE-IUL, Portugal.
October 2006 - March 2007	Research Assistant, Project ‘European Social Survey’, Instituto de Ciências Sociais, Universidade de Lisboa, Portugal.
March 2005 - April 2005	Interviewer, Project ‘Evaluation and Security of the Social Responses of Rehabilitation and Integration of Disabled People’, IESE/CIES, Portugal.
June 2003 - August 2003	Interviewer, Project ‘West Immigrants in Portugal: from emigration to integration’, CESIS, Portugal.

3.2. Publications

3.2.1. Journal Articles (referee system) - International

Hilário, A.P. (forthcoming) Preferences around the disclosure of dying: a vision from Portuguese society. *Palliative & Supportive Care* (0,611 SJR2017 / Q2 Medicine)

Hilário, A. P. (2019) (Re) Making gender in the clinical context: a look at how ideologies shape the medical construction of Gender Dysphoria in Portugal. *Social Theory & Health* DOI: 10.1057/s41285-019-00102-3 (0,554 SJR2017 / Q2 Health - Social Science)

Augusto, F. R. & Hilário, A. P. (2019) “Through the looking glass”: the emotional journey of the volunteer ethnographer when researching sensitive topics with vulnerable populations. *The Qualitative Report*, 24(13) (0,334 SJR2017 / Q1 Cultural Studies)

Hilário, A. P. (2018) Rethinking trans identities within the medical and psychological community: a path towards the depathologisation and self-definition of gender identification in Portugal? *Journal of Gender Studies* DOI: 10.1080/09589236.2018.1544066 (0,434 SJR2017 / Q2 Arts and Humanities)

Hilário, A. P. (2017) Contestation, instrumental resistance and strategic conformation within the diagnostic process of Gender Dysphoria in Portugal. *Health: an interdisciplinary journal for the social study of health, illness and medicine*, 21(5): 555-572. DOI: 10.1177/1363459317708826 (0,524 SJR2017 / Q2 Health - Social Science)

Hilário, A. P. (2016) The Stigma Experienced by Terminally Ill Patients: Evidence From a Portuguese Ethnographic Study. *Journal of Social Work in End-of-Life & Palliative Care*, 12 (4): 331-347. DOI: 10.1080/15524256.2016.1247770 (0,345 SJR2016 / Q3 Health - Social Science)

Hilário, A. P. (2016) Witnessing a body in decline: Men's and women's perceptions of an altered physical appearance. *Journal of Women & Aging*. DOI:10.1080/08952841.2015.1065142 (0,525 SJR2016 / Q2 Gender Studies)

Hilário, A. P. (2016) In-patient hospice: A qualitative study with Portuguese patients, family and staff. *Death Studies*, 40(5): 290-297. DOI:10.1080/07481187.2015.1132283 (0,571 SJR2016 / Q2 Arts and Humanities)

Hilário, A. P. (2015) Making sense of a changed physical body: Why gender matters at end of life. *Journal of Aging Studies*, 33: 58–66. DOI: 10.1016/j.jaging.2015.03.001 (0,924 SJR2015 / Q1 Health Policy)

3.2.2. Journal Articles (referee system) - Portuguese

Hilário, A. P. (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.

3.2.3. Book Chapters

Hilário, A. P. (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. pp.123-134.

Hilário, A. P. (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. pp.141-156.

3.2.4. Working Papers

Hilário, A. P. (2012) What about dignity? The meaning and experience of terminally ill patients. *CIES e-Working Paper N° 122/2012*, Lisboa: CIES, ISCTE-IUL.

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

3.2.5. Conference Proceedings

Hilário, A. P. (2008) Enfrentando o fantasma da morte: as estratégias negociadas e as lógicas partilhadas pelos enfermeiros de um serviço de cuidados paliativos. Ata de Conferência, *VI Congresso da Associação Portuguesa de Sociologia*, Lisboa: Universidade Nova de Lisboa.

3.2.6. Research Reports

Torres, A. Pegado, E. Sarmiento, M. Hilário, A.P. Freitas, A. Sousa, I. Cruz, R. Penha, R. (2009) *Estudo de Diagnóstico e Avaliação das Comissões de Protecção de Crianças e Jovens - Sinopse*, Lisboa: CIES, ISCTE-IUL.

Torres, A. Pegado, E. Sarmiento, M. Hilário, A.P. Freitas, A. Sousa, I. Cruz, R. Penha, R. (2008) *Estudo de Diagnóstico e Avaliação das Comissões de Protecção de Crianças e Jovens. Volume Complementar IV: Dossier de casos mediatizados*. Lisboa: CIES, ISCTE-IUL.

Torres, A. Pegado, E. Sarmiento, M. Hilário, A.P. Freitas, A. Sousa, I. Cruz, R. Penha, R. (2008) *Estudo de Diagnóstico e Avaliação das Comissões de Protecção de Crianças e Jovens. Volume Complementar III: Relatos de Casos acompanhados pelas CPCJ*. Lisboa: CIES, ISCTE-IUL.

Torres, A. Pegado, E. Sarmiento, M. Hilário, A.P. Freitas, A. Sousa, I. Cruz, R. Penha, R. (2008) *Estudo de Diagnóstico e Avaliação das Comissões de Protecção de Crianças e Jovens. Volume Complementar II: Sistemas de Protecção de vários países*. Lisboa: CIES, ISCTE-IUL.

Torres, A. Pegado, E. Sarmiento, M. Hilário, A.P. Freitas, A. Sousa, I. Cruz, R. Penha, R. (2008) *Estudo de Diagnóstico e Avaliação das Comissões de Protecção de Crianças e Jovens. Volume complementar I: Análise dos Relatórios das Actividades das CPCJ*. Lisboa: CIES, ISCTE-IUL.

Torres, A. Pegado, E. Hilário, A.P. Cruz, R. Penha, A. R. Freitas, A. Sousa, I. Sarmiento (2008) *Estudo de Diagnóstico e Avaliação das Comissões de Protecção de Crianças e Jovens: Relatório Final*. Lisboa: CIES, ISCTE-IUL.

3.3. Oral Presentations

Hilário, A. P. (2018) Deambulações em torno do papel dos animais no final da vida humana, *Conferência Animais-companheiros nas vidas dos humanos*, Lisbon: Instituto de Ciências Sociais, Universidade de Lisboa, 8-9 November.

Augusto, F. R. & Hilário, A. P. (2018) Through the looking glass: the emotional journey of the volunteer ethnographer when researching sensitive topics with vulnerable populations, *3rd World Conference on Qualitative Research*, Lisbon: ESEL, 17-19 October.

Hilário, A. P. (2018) The nuances of the diagnosis of Gender Dysphoria: understanding how ideologies constrain diagnostic attribution and access to healthcare, *17th Biennial Conference: Old Tensions, Emerging Paradoxes in Health: Rights and Knowledge*. Lisbon: Instituto Universitário de Lisboa, ISCTE-IUL, 7-8 June.

Hilário, A. P. (2018) Between contestation and acceptance: the nuances of the diagnosis of Gender Dysphoria, *17th Biennial Conference: Old Tensions, Emerging Paradoxes in Health: Rights and Knowledge*. Lisbon: Instituto Universitário de Lisboa, ISCTE-IUL, 7-8 June.

Hilário, A. P. (2018) Desafios na investigação em torno da morte e do processo de morrer: um olhar a partir de um estudo de caso com doentes terminais, familiares e profissionais de cuidados paliativos. *Seminário RRI: Considerações Éticas na Pesquisa com Sujeitos Vulneráveis*. Lisboa: Instituto de Ciências Sociais, Universidade de Lisboa, 14 February.

Hilário, A. P. (2017) Beyond the Transgender diagnosis: contestation, instrumental resistance and strategic conformation of Trans people in Portugal, *BSA 49th Medical Sociology Annual Conference*, York: York University, 13-15 September.

Hilário, A. P. (2017) (Re) Making gender in the clinical context: a look into how gender ideologies shape the medical construction of Gender Dysphoria, *13th European Sociological Association Conference*, Athens: PANTHEON University, 29 August - 1 September.

Hilário, A. P. (2016) The hospice as a non-liminal space: evidence from a qualitative study with Portuguese terminally ill patients, family members and staff, *ESA RN16 Mid-Term Conference*, Lisbon: Faculdade de Ciências Sociais e Humanas, Universidade Nova de Lisboa, 19-21 May.

Hilário, A. P. (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, A. P. (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, A. P. (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, A. P. (2012) Making Sense of Terminal Illness. *International Conference on Challenges for Health and Health Care in Europe*, Aalborg: Aalborg University, 1-2 November.

Hilário, A. P. (2012) Um olhar sobre a pesquisa etnográfica no final da vida. *V Congresso Ibero-americano de Pesquisa Qualitativa*, Lisbon: Instituto Superior de Ciências Sociais e Políticas, Universidade de Lisboa, 11-13 October.

Hilário, A. P. (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, A. P. (2011) What about dignity: the meaning and experience of terminally ill patients. *10th European Sociological Association Conference*, Geneve: Uni Mail, 7-10 September.

Hilário, A. P. (2011) Challenges in end of life research: the story of a journey. *10th European Sociological Association Conference*, Geneve: Uni Mail, 7-10 September.

Hilário, A. P. (2011) The unbounded dying body: stories of terminally ill patients. *PhD Research Day*, London: Royal Holloway University of London, 15 June.

Hilário, A. P. (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, A. P. (2010) Understanding dignity at the end of life: the experience of palliative care patients. *7th Global Conference Making Sense of: Dying and Death*, Prague: Michna Palace, 8-10 November.

Hilário, A. P. (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, A. P. (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: Instituto Universitário de Lisboa, ISCTE-IUL, 2-5 September.

Hilário, A. P. (2009) The corporeal realities of dying patients: core reflections. *The British Sociological Association Annual Conference*: Cardiff, Cardiff City Hall, 16-18 April.

Hilário, A. P. (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: Faculdade de Ciências Sociais e Humanas, Universidade Nova de Lisboa, 25-28 June.

Hilário, A. P. (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, A. P. (2006) The conspiracy of silence: contributions for a new sociological approach about death and dying. *III International Forum Criteos*, Lisbon: Instituto Universitário de Lisboa, ISCTE-IUL, 23-25 November.

3.5. Oral presentations by invitation

Hilário, A. P. (2017) Olhares sobre a intimidade da morte. *Seminário Temático A gestão política do corpo difícil pelos profissionais da Saúde, da Educação e do Serviço Social*, Lisboa: Universidade Nova de Lisboa, Faculdade de Ciências Sociais e Humanas, 29 November.

Hilário, A. P. (2016) Conceito e experiência de dignidade em pessoas com doença terminal. *VIII Congresso Nacional de Cuidados Paliativos da Associação Portuguesa de Cuidados Paliativos*, Lisboa: Centro de Congressos da Universidade Católica Portuguesa, 7-9 April.

3.6. Coordination and organization of conferences and scientific meetings

Research Network of Sociology of Health and Illness, European Sociological Association, *12th European Sociological Association Conference*, Czech Technical University, Prague, Czech Republic, 25-29 August 2015.

Research Network of Sociology of Health and Illness, European Sociological Association, *11th European Sociological Association Conference*, Torino University, Torino, Italy, 29 August - 1 September 2013.

3.7. Coordination of scientific session

Ir para além do óbvio: (re) pensar a pesquisa etnográfica com sujeitos vulneráveis, coordinated by Hilário, A. P. & Augusto, F. R. VII Congresso da Associação Portuguesa de Antropologia, Universidade Nova de Lisboa, Lisboa, Portugal, 4-7 June 2019.

Listening to the voices of children: how to bring them into the sociology of health and illness, coordinated by Hilário, A.P. *Mid-Term Conference of the Research Network of Sociology of Health and Illness*, Universidade Nova de Lisboa, Lisbon, Portugal, 19-21 May 2016.

The Impact of Gender, Class and Ethnicity on End of life Experiences, coordinated by Hilário, A. P. *12th European Sociological Association Conference*, Czech Technical University, Prague, Czech Republic, 25-29 August 2015.

3.8. Panel Chair

Embodiments and Institutions, *Trans+Formations Conference: Lives and Politics Beyond the Gender Binary*, Instituto de Ciências Sociais, Lisbon, Portugal, 14-15 June 2016.

The Transrights Project: Snapshots, *Trans+Formations Conference: Lives and Politics Beyond the Gender Binary*, Instituto de Ciências Sociais, Lisbon, Portugal, 14-15 June 2016.

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*, European Sociological Association, Universidade Nova de Lisboa, Lisbon, Portugal, 19-21 May 2016.

The Politics of Healthcare and Illness Management, *12th European Sociological Association Conference*, Czech Technical University, Prague, Czech Republic, 25-29 August 2015.

Health and Illness in Mediterranean Countries: Present Challenges and Future Developments, *12th European Sociological Association Conference*, Czech Technical University, Prague, Czech Republic, 25-29 August 2015.

Chronic Illness II: Experiences and Recognition, *11th European Sociological Association Conference*, Torino University, Torino, Italy, 29 August - 1 September 2013.

3.9. Awards and distinctions

Scientific Employment Stimulus 2017, Portuguese Foundation of Science & Technology (FCT), Portugal.

Doctoral Fellowship 2008/2012, Portuguese Foundation of Science & Technology (FCT), Portugal.

Academic Merit Scholar 2004/2005, Degree in Sociology and Planning, Instituto Universitário de Lisboa, Portugal.

Academic Merit Scholar 2004/2005, Degree in Sociology and Planning, Ministério da Educação, Portugal.

4. Teaching experience

4.1. Coordination of courses

Dates	Cicle of Studies	Course	Institution
March 2015 – July 2015	1º cicle (Undergraduate)	Antropossociology and Field Work	Instituto Piaget, Almada, Portugal

4.2. Lecturer

Dates	Cicle of Studies	Course/Module	Institution
February 2019	3º cicle (PhD Open Soc)	Module ‘Ethical, methodological and practical dilemmas of conducting research on death and the process of dying’	Instituto de Ciências Sociais, Universidade de Lisboa
October 2018 – February 2019	1º cicle (Degree in Nursing)	Social Sciences & Humanities I	Escola de Enfermagem – Instituto Politécnico de Santarém
October 2016	3º cicle (PhD Open Soc)	Module ‘Gender contributions for the sociology of death and dying: a look from an ethnographic perspective’	Instituto de Ciências Sociais, Universidade de Lisboa

March 2015 – July 2015	1º cicle (Degree in Psychology and Human Motricity)		Antropossociology and Field Work	Instituto Piaget
June 2013	2º cicle (Master in Palliative Care)	in	Module ‘Ethnographic Research’	Faculdade de Medicina, Universidade de Lisboa
May 2012	2º cicle (Master in Palliative Care)	in	Module ‘Ethnographic Research’	Faculdade de Medicina, Universidade de Lisboa
July 2011	2º cicle (Master in Radiotherapy)	in	Module ‘Body, Death and Society’	Escola Superior de Tecnologias da Saúde de Lisboa
May 2011	2º cicle (Master in Palliative Care)	in	Module ‘Ethnographic Research’	Faculdade de Medicina, Universidade de Lisboa
September 2010	1º cicle (Degree in Medicine)	in	Module ‘Death and Society’	Faculdade de Medicina, Universidade de Lisboa
May 2010	2º cicle (Master in Palliative Care)	in	Module ‘Ethnographic Research’	Faculdade de Medicina, Universidade de Lisboa

4.3. Participation in Academic Juries

4.3.1. Masters

Ana Catarina Rodrigues Correia, Faculdade de Letras da Universidade do Porto, 2016.

4.3.2. Doctoral

Ana Inês Pedro Martins Vicente, Faculdade de Ciências Sociais e Humanas da Universidade de Lisboa, 2019.

5. University extension and knowledge dissemination

5.1. Knowledge dissemination

Hilário, A. P. (2008) O cuidar em fim de vida, *Jornal Meia Hora*, 19/05/2008

5.2. Participation in activities of scientific promotion

Co-editor Newsletter, Research Network of Sociology of Health and Illness, European Sociological Association (4 Issues), September 2011 - August 2015.

Co-organizer Scientific Internship 'Ser Sociólogo(a) por 15 dias', Centro de Investigação e Estudos em Sociologia, Instituto Universitário de Lisboa, ISCTE, July 2007.

6. University service

6.1. Participation in scientific networks

PhD Representative, Research Network of Sociology of Health and Illness, European Sociological Association, September 2013 - August 2015.

Board Member, Research Network of Sociology of Health and Illness, European Sociological Association, September 2011 - August 2015.

6.2. Editorial/Referee Activity

Since 2019 Societies (1 paper)

Práxis Educativa (1 paper)

Saúde e Sociedade (1 paper)

Since 2018 Social Theory & Health (1 paper)

Since 2017 Interface - Comunicação, Saúde, Educação (2 papers)

Death Studies (1 paper)

Since 2016 Health: An Interdisciplinary Journal for the Social Study of Health, Illness and Medicine (2 papers)

Health and Social Care in the Community (1 paper)

Palliative Medicine (1 paper)

6.3. Other activities

External Jury, Centro de Estudos Judiciários, Concurso de Acesso ao 35º Curso de Formação de Magistrados para os Tribunais Judiciais, March 2019.

External Jury, Centro de Estudos Judiciários, Concurso de Acesso ao 33º Curso de Formação de Magistrados para os Tribunais Judiciais, March 2017.

Ana Patrícia Hilário, 2nd May 2019