

CALM PUBLICATIONS LIST

A. TORONTO CALM TEAM PUBLICATIONS

INCLUDING *DEATH AND DYING DISTRESS SCALE (DADDS) / DEATH ANXIETY PAPERS & **OTHER CALM- RELATED PUBLICATIONS (E.G., REVIEW PAPERS & CHAPTERS):

i) Submitted for Publication

Mah K, Shapiro G, Hales S, Rydall A, Malfitano C, An E, Nissim R, Li M, Zimmermann C, Rodin G. The impact of attachment security on death preparation in advanced cancer: The role of couple communication. *Revision requested October 2019.*

**Troncoso P, Malfitano C, Rydall A, Hales S, Rodin G. A review of psychosocial interventions for patients with advanced cancer in Latin America: The potential value of CALM Therapy in this setting. *Revision requested July 2019.*

**Troncoso P, Rydall A, Hales S, Rodin G. Psico-oncología en Cáncer Avanzado: Terapia CALM Una Intervención Canadiense [Spanish]. [Psycho-oncology in advanced cancer: CALM Therapy a Canadian intervention]. *Submitted for publication 2019.*

ii) Accepted for Publication / Epub Ahead of Print / In Press

Shaw C, Lo C, Lanceley A, Hales S, Rodin G. (In press). The assessment of mentalization: Measures for the patient, the therapist and the interaction. Journal of Contemporary Psychotherapy. 8 April 2019 [Epub ahead of print].
<https://link.springer.com/article/10.1007%2Fs10879-019-09420-z>

**Rodin G, An E, Shnall J, Malfitano C. (In press). Psychological interventions for patients with advanced disease: Implications for oncology and palliative care. Journal of Clinical Oncology. *In press.*

*An E, Wennberg E, Nissim R, Lo C, Hales S, Rodin G. (In press). Death talk and relief of death-related distress in patients with advanced cancer. BMJ Supportive & Palliative Care. [Published Online First: 02 August 2017]. [doi: 10.1136/bmjspcare-2016-001277](https://doi.org/10.1136/bmjspcare-2016-001277)

iii) Published

Lo C, Hales S, Chiu A, Panday T, Malfitano C, Jung J, Rydall A, Li M, Nissim R, Zimmermann C, Rodin G. Managing Cancer And Living Meaningfully (CALM): Randomized feasibility trial in patients with advanced cancer. BMJ Supportive & Palliative Care. 2019 Jun; 9(2): 209-218. [Epub 2016 Jan 19]. [doi: 10.1136/bmjspcare-2015-000866](https://doi.org/10.1136/bmjspcare-2015-000866)

Shaw C, Chryssikou V, Lanceley A, Lo C, Hales S, Rodin G. Mentalization in CALM psychotherapy sessions: Helping patients engage with alternative perspectives at the end of life. Patient Education and Counseling. 2019 Feb; 102(2):188-197. [Epub 2018 Oct 3]. [doi: 10.1016/j.pec.2018.10.001](https://doi.org/10.1016/j.pec.2018.10.001)

Vehling S, Tian Y, Malfitano C, Shnall J, Watt S, Mehnert A, Rydall A, Zimmermann C, Hales S, Lo C, Rodin G. Attachment security and existential distress among patients with advanced cancer. Journal of Psychosomatic Research. 2019 Jan; 116:93-99. [Epub 2018 Nov 27]. [doi: 10.1016/j.jpsychores.2018.11.018](https://doi.org/10.1016/j.jpsychores.2018.11.018)

Updated: October 8, 2019

An E, Lo C, Hales S, Zimmermann C, Rodin G. Demoralization and death anxiety in advanced cancer. Psycho-Oncology. 2018 Nov; 27(11): 2566-2572. [Epub 2018 Aug 20]. [doi: 10.1002/pon.4843](https://doi.org/10.1002/pon.4843)

**Kaasa S, Loge JH, Aapro M, Albreht T, Anderson R, Bruera E, Brunelli C, Caraceni A, Cervantes A, Currow DC, Deliens L, Fallon M, Gómez-Batiste X, Grotmol KS, Hannon B, Haugen DF, Higginson IJ, Hjermstad MJ, Hui D, Jordan K, Kurita GP, Larkin PJ, Miccinesi G, Nauck F, Pribakovic R, Rodin G, Sjøgren P, Stone P, Zimmermann C, Lundebj T. Integration of oncology and palliative care: A Lancet Oncology Commission. Lancet Oncology. 2018 Nov; 19(11):e588-e653. [Epub 2018 Oct 18]. [doi: 10.1016/S1470-2045\(18\)30415-7](https://doi.org/10.1016/S1470-2045(18)30415-7)

**Rodin G. From evidence to implementation: the global challenge for psychosocial oncology. Psycho-Oncology. 2018 Oct.; 27(10): 2310-2316. [doi: 10.1002/pon.4837](https://doi.org/10.1002/pon.4837)

Rodin G, Lo C, Rydall A, Shnall J, Malfitano C, Chiu A, Panday T, Watt S, An E, Nissim R, Li M, Zimmermann C, Hales S. Managing Cancer And Living Meaningfully (CALM): A randomised controlled trial of a psychological intervention for patients with advanced cancer. Journal of Clinical Oncology. 2018 Aug 10; 36(23): 2422-2432. [Epub 2018 Jun 29] [Open Access Publication]. [doi: 10.1200/JCO.2017.77.1097](https://doi.org/10.1200/JCO.2017.77.1097)

Colosimo K, Nissim R, Pos AE, Hales S, Zimmermann C, Rodin G. "Double awareness" in psychotherapy for patients living with advanced cancer. Journal of Psychotherapy Integration. 2018 Jun; 28(2): 125-140. <http://dx.doi.org/10.1037/int0000078>

*Vehling S, Malfitano C, Shnall J, Watt S, Panday T, Chiu A, Rydall A, Zimmermann C, Hales S, Rodin G, Lo C. A concept map of death-related anxieties in patients with advanced cancer. BMJ Supportive & Palliative Care. 2017 Dec; 7(4): 427-434. [Epub 2017 Aug 2]. [doi: 10.1136/bmjspcare-2016-001287](https://doi.org/10.1136/bmjspcare-2016-001287)

**Rodin GM. Psychotherapeutic interventions near the end of life: Theory, evidence, and future directions (Invited Commentary – Special Issue: Psychology and End-of-Life). Australian Psychologist. 2017 Oct; 52(5): 335-339. [Epub 2017 Sep 20]. [doi: 10.1111/ap.12307](https://doi.org/10.1111/ap.12307)

Shaw C, Chrysikou V, Davis S, Gessler S, Rodin G, Lanceley A. Inviting end-of-life talk in initial CALM therapy sessions: A conversation analytic study. Patient Education and Counseling. 2017 Feb; 100(2): 259-266. [doi: 10.1016/j.pec.2016.08.024](https://doi.org/10.1016/j.pec.2016.08.024)

*Tong E, Deckert A, Gani N, Nissim R, Rydall A, Hales S, Rodin G, Lo C. The meaning of self-reported death anxiety in advanced cancer. Palliative Medicine. 2016 Sep; 30(8): 772-779. [Epub 2016 Feb 8]. [doi: 10.1177/0269216316628780](https://doi.org/10.1177/0269216316628780)

*Neel C, Lo C, Rydall A, Hales S, Rodin G. Determinants of death anxiety in patients with advanced cancer. BMJ Supportive and Palliative Care. 2015 Dec; 5(4): 373-380. [Epub 2013 Aug 22]. [doi: 10.1136/bmjspcare-2012-000420](https://doi.org/10.1136/bmjspcare-2012-000420)

Lo C, Hales S, Rydall A, Panday T, Chiu A, Malfitano C, Jung J, Li M, Nissim R, Zimmermann C, Rodin G. Managing Cancer And Living Meaningfully: Study protocol for a randomized controlled trial. Trials. 2015 Sep 3; 16:391. [Open Access; <https://doi.org/10.1186/s13063-015-0811-1>] [doi: 10.1186/s13063-015-0811-1](https://doi.org/10.1186/s13063-015-0811-1)

*Krause S, Rydall A, Hales S, Rodin G, Lo C. Initial validation of the Death and Dying Distress Scale for the assessment of death anxiety in patients with advanced cancer. Journal of Pain and

Symptom Management. 2015 Jan; 49(1): 126-134. [Epub 2014 May 28]. doi: [10.1016/j.jpainsymman.2014.04.012](https://doi.org/10.1016/j.jpainsymman.2014.04.012)

****Hales S, Lo C, Rodin G. (2015). Managing Cancer And Living Meaningfully (CALM) Therapy (Chapter 62). In: Holland JC, Breitbart WS, Butow PN, Jacobsen PB, Loscalzo MJ, McCorkle R (Editors). Psycho-Oncology, Third Edition. Oxford University Press: New York, NY; pp. 487-491.**

Lo C, Hales S, Jung J, Chiu A, Panday T, Rydall A, Nissim R, Malfitano C, Petricone-Westwood D, Zimmermann C, Rodin G. Managing Cancer And Living Meaningfully (CALM): Phase 2 trial of a brief individual psychotherapy for patients with advanced cancer. Palliative Medicine 2014; 28(3): 234-242. <https://doi.org/10.1177%2F0269216313507757>

Nissim R, Freeman E, Lo C, Zimmermann C, Gagliese L, Rydall A, Hales S, Rodin G. Managing Cancer and Living Meaningfully (CALM): A qualitative study of a brief individual psychotherapy for individuals with advanced cancer. Palliative Medicine 2012; 26(5): 713-721. <https://doi.org/10.1177/0269216311425096>

****Li M, Fitzgerald P, Rodin G. Evidence-based treatment of depression in patients with cancer. Journal of Clinical Oncology** 2012 Apr; 30(11): 1187-1196. [Epub 2012 Mar 12]. <https://ascopubs.org/doi/10.1200/JCO.2011.39.7372>

****Fitzgerald P, Nissim R, Rodin G. (2012). A life-stage approach to psycho-oncology (Chapter 12). In: Grassi L & Riba M (Editors.). Clinical Psycho-Oncology: An International Perspective, First Edition. Wiley & Sons, Ltd., United Kingdom; pp. 155-163.** <https://onlinelibrary.wiley.com/doi/book/10.1002/9781119941101>

****Li M, Boquiren V, Lo C, Rodin G. (2011). Depression and anxiety in supportive oncology (Chapter 52). In: Davis MP, Fever P, Ortnier P, Zimmermann C (Editors). Supportive Oncology, First Edition. Elsevier, Philadelphia, PA; pp. 528-540.** <https://www.elsevier.com/books/supportive-oncology/9781437710151>

*Lo C, Hales S, Zimmermann C, Gagliese L, Rydall A, Rodin G. Measuring death-related anxiety in advanced cancer: Preliminary psychometrics of the death and dying distress scale. Journal of Pediatric Hematology & Oncology 2011 Oct; 33(Suppl 2): S140-145. https://journals.lww.com/jpho-online/Fulltext/2011/10001/Measuring_Death_related_Anxiety_in_Advanced.15.aspx

****Kissane DW, Levin T, Hales S, Lo C, Rodin G. (2011). Psychotherapy for depression in cancer and palliative care (Chapter 8). In: Kissane DW, Maj M, Sartorius N (Editors). Depression and Cancer. Wiley-Blackwell, United Kingdom; pp. 177-206.** <https://www.wiley.com/en-ca/Depression+and+Cancer-p-9781119957539>

B. GERMAN CALM TEAM PUBLICATIONS

i) Published

Oberstadt MCF, Esser P, Classen J, Mehnert A. Alleviation of psychological distress and the improvement of quality of life in patients with Amyotrophic Lateral Sclerosis: Adaptation of a short-term psycho-therapeutic intervention. Frontiers in Neurology. 16 April 2018; Volume 9, Article 231. [Open Access] <https://doi.org/10.3389/fneur.2018.00231>

Grünke B, Philipp R, Vehling S, Scheffold K, Härter M, Oechsle K, Schulz-Kindermann F, Mehnert A, Lo C. Measuring the psychosocial dimensions of quality of life in advanced cancer patients: Psychometrics of the German Quality of Life at the End of Life–Cancer–Psychosocial (QUAL-EC-P) Questionnaire. *Journal of Pain and Symptom Management*. 2018 Mar; 55(3): 985-991.e1. [Epub 2017 Nov 16]. [doi: 10.1016/j.jpainsymman.2017.11.006](https://doi.org/10.1016/j.jpainsymman.2017.11.006)

Scheffold K, Engelmann D, Schulz-Kindermann F, Rosenberger C, Krüger A, Rodin G, Härter M, Mehnert A. “Managing Cancer and Living Meaningfully”: Qualitative pilotergebnisse einer sinnbasierten kurzzeittherapie für fortgeschritten erkrankte krebspatienten (CALM) [German]. *Psychotherapeut*. [Managing Cancer and Living Meaningfully: Qualitative pilot findings based on a brief therapy for advanced cancer patients (CALM). *Psychotherapist*]. 2017 May; 62(3): 243-248. [Epub 2017 March 29]. <https://doi.org/10.1007/s00278-017-0179-7>

Engelmann D, Scheffold K, Friedrich M, Hartung TJ, Schulz-Kindermann F, Lordick F, Schilling G, Lo C, Rodin G, Mehnert A. Death-related anxiety in patients with advanced cancer: Validation of the German version of the Death and Dying Distress Scale. *Journal of Pain and Symptom Management*. 2016 Oct; 52(4): 582-587. [doi: 10.1016/j.jpainsymman.2016.07.002](https://doi.org/10.1016/j.jpainsymman.2016.07.002)

Scheffold K, Philipp R, Engelmann D, Schulz-Kindermann F, Rosenberger C, Oechsle K, Härter M, Wegscheider K, Lordick F, Lo C, Hales S, Rodin G, Mehnert A. Efficacy of a brief manualized intervention Managing Cancer and Living Meaningfully (CALM) adapted to German cancer care settings: Study protocol for a randomized controlled trial. *BMC Cancer*. 2015 Aug 19;15(1):592. [BioMed Central Open Access publication]. [doi: 10.1186/s12885-015-1589-y](https://doi.org/10.1186/s12885-015-1589-y)

C. ITALIAN CALM TEAM PUBLICATIONS

i) Accepted for Publication / Epub Ahead of Print / In Press

Caruso R, Nanni MG, Rodin G, Lo C, Sabato S, Grassi L. (In press). Efficacy of a brief manualized intervention Managing Cancer and Living Meaningfully (CALM) adapted to Italian cancer care setting. Study protocol for a randomized controlled trial. *Trials*. *Accepted for publication 2019*.

D. REGISTERED COPYRIGHTS

Rodin G, Hales S, Lo C. Managing Cancer And Living Meaningfully (CALM) Treatment Manual: An individual psychotherapy for patients with advanced disease. Canadian Intellectual Property Office. Date of issue: 2015-09-04. Filing date: 2015-09-04; Copyright#: 1124205.

E. REGISTERED CLINICAL TRIALS

ClinicalTrials.gov Identifier: NCT01506492 (status: completed)

Title: Managing Cancer and Living Meaningfully (CALM): A Study to Evaluate the Effectiveness of a Psychological Intervention for Cancer Patients.

Principal Investigators: G. Rodin, S. Hales, C. Lo, Princess Margaret Cancer Centre, University Health Network, Toronto, Canada

Funding Agency: Canadian Institutes of Health Research (Grant #MOP106473)

[ClinicalTrials.gov Identifier: NCT02353546 \(status: completed\)](#)

Title: Managing Cancer and Living Meaningfully (CALM): Phase 2b Pilot Randomized Psychotherapy Trial in Patients With Advanced Cancer.

Principal Investigators: G. Rodin, S. Hales, C. Lo, Princess Margaret Cancer Centre, University Health Network, Toronto, Canada

Funding Agency: Canadian Institutes of Health Research (Grant #MOP106473)

[ClinicalTrials.gov Identifier: NCT02051660 \(status: completed\)](#)

Title: German Evaluation of the Effectiveness of the Psychological Intervention Managing Cancer and Living Meaningfully (CALM).

Principal Investigator: A. Mehnert, University of Leipzig, Leipzig, Germany

Collaborators: University of Leipzig, University of Hamburg, and University Health Network

Funding Agency: German Cancer Aid

[ClinicalTrials.gov Identifier: NCT03068013 \(status: recruiting\)](#)

Title: Effectiveness of a Brief Manualized Intervention Managing Cancer and Living Meaningfully (CALM) Adapted to the Italian Cancer Care Setting (CALM-IT). Study Protocol for a Randomized Controlled Trial

Study Chair: L. Grassi, MD, Istituto di Psichiatria, Dipartimento di Scienze Biomediche e Chirurgico Specialistiche, Università degli Studi di Ferrara.

Contact: R. Caruso, MD, PhD, Istituto di Psichiatria, Dipartimento di Scienze Biomediche e Chirurgico Specialistiche, Università degli Studi di Ferrara.

Collaborators: Princess Margaret Cancer Centre, University Health Network

Funding Agency/Sponsor: Università degli Studi di Ferrara

[ClinicalTrials.gov Identifier: NCT02051660 \(status: completed\)](#)

Title: Efficacy of a Brief Manualized Intervention Managing Cancer and Living Meaningfully (CALM) Adapted to Italian Cancer Care Setting. Study Protocol for a Randomized Controlled Trial

Study Chair: L. Grassi, MD, Istituto di Psichiatria, Dipartimento di Scienze Biomediche e Chirurgico Specialistiche, Università degli Studi di Ferrara.

Principal Investigator: R. Caruso, MD, PhD, Istituto di Psichiatria, Dipartimento di Scienze Biomediche e Chirurgico Specialistiche, Università degli Studi di Ferrara.

Collaborators: Princess Margaret Cancer Centre, University Health Network

Funding Agency/Sponsor: Università degli Studi di Ferrara

F. VALIDATION & RELATED PAPERS RE- DADDS, ECR-16, QUAL-EC & ESAS

1. Grünke B, Philipp R, Vehling S, Scheffold K, Härter M, Oechsle K, Schulz-Kindermann F, Mehnert A, Lo C. **Measuring the Psychosocial Dimensions of Quality of Life in Patients With Advanced Cancer: Psychometrics of the German Quality of Life at the End of Life-Cancer-Psychosocial Questionnaire. Journal of Pain and Symptom Management. 2018 Mar; 55(3):985-991.e1. doi: 10.1016/j.jpainsymman.2017.11.006. Epub 2017 Nov 16.**

ABSTRACT:

CONTEXT: Quality of life (QoL) is a central focus of care in advanced cancer. Specialized instruments, such as the Quality of Life at the End of Life-Cancer (QUAL-EC), may be useful to assess psychosocial issues associated with QoL unique to this population.

OBJECTIVES: To evaluate the measurement of the psychosocial dimensions of QoL using the German translation of the QUAL-EC-Psychosocial (QUAL-EC-P) questionnaire, including factor structure and psychometrics.

Updated: October 8, 2019

METHODS: About 183 patients with advanced cancer from the University Medical Center Hamburg-Eppendorf and University Medical Center Leipzig completed the QUAL-EC-P questionnaire. We conducted exploratory factor analysis as well as item and reliability analysis. We examined convergent validity with correlations between the scale and relevant psychological constructs.

RESULTS: The sample was 60% female with mean age of 57.7 (SD = 11.7). We extracted three factors accounting for 44% of the variance aligning with the structure of the instrument. The QUAL-EC-P questionnaire showed good to acceptable internal consistency for the QoL- psychosocial total score ($\alpha = 0.77$), the Life completion subscale ($\alpha = 0.77$), and the Relationship with health care provider subscale ($\alpha = 0.81$). The Preparation for end of life subscale had adequate albeit low internal consistency ($\alpha = 0.64$) because concerns about family were less associated with financial worry and fear of death than expected. The psychosocial dimensions of QoL correlated negatively with depression ($r = -0.27$, $P \leq 0.001$), anxiety ($r = -0.32$, $P \leq 0.001$), demoralization ($r = -0.63$, $P \leq 0.001$), and attachment insecurity ($r = -0.51$, $P \leq 0.001$) and positively with spiritual well-being ($r = 0.63$, $P \leq 0.001$).

CONCLUSION: The QUAL-EC-P questionnaire may be used to assess the psychosocial aspects of QoL and promote their clinical discussion in patients with advanced cancer.

DOI: 10.1016/j.jpainsymman.2017.11.006

PMID: 29155291 [Indexed for MEDLINE]

2. Philipp R, Vehling S, Scheffold K, Grünke B, Härter M, Mehnert A, Oechsle K, Schulz-Kindermann F, Lo C. Attachment Insecurity in Advanced Cancer Patients: Psychometric Properties of the German Version of the Brief Experiences in Close Relationships Scale (ECR-M16-G). Journal of Pain and Symptom Management. 2017 Oct; 54(4):555-562. doi: 10.1016/j.jpainsymman.2017.07.026. Epub 2017 Jul 15.

ABSTRACT:

CONTEXT: Attachment insecurity refers to difficulty in trusting and relying on others in times of need. Its underlying factors attachment anxiety and attachment avoidance have been empirically associated with impaired coping in advanced cancer and, therefore, should be considered in individually tailored medical and psychosocial treatment.

OBJECTIVES: The objective of this study was to evaluate the psychometric properties of the German translation of the Brief Experiences in Close Relationships Scale (ECR-M16-G).

METHODS: We recruited 182 advanced cancer patients from outpatient psycho-oncology clinics of the University Medical Center Hamburg-Eppendorf and the University Medical Center Leipzig, local and external cancer care facilities. We performed confirmatory factor analysis to replicate the higher order factor structure reported in previous research. We conducted item and reliability analysis, also correlation analysis, to examine concurrent validity.

RESULTS: One hundred fifty-eight patients completed the ECR-M16-G (women 61%, mean age 57.9, SD = 11.1). We replicated the factor structure with the subscales Attachment Anxiety and Attachment Avoidance as second-order factors and Worrying about relationships, Frustration about unavailability, Discomfort with close others, and Turning away from others as first-order factors. An adjusted model that interchanged factor loadings of items 4 and 10 showed good fit (Comparative Fit Index = 0.94, Non-Normed Fit Index = 0.93, root mean square error of approximation = 0.05). Subscales showed acceptable to good internal consistency (anxiety $\alpha = .81$ and avoidance $\alpha = .78$). Attachment insecurity (mean = 3.1, SD = 1.0) was positively associated with depression, anxiety, demoralization ($P < 0.001$), and symptom burden ($P = 0.02$) and negatively associated with spiritual well-being ($P < 0.001$).

CONCLUSION: The ECR-M16-G is a valid and reliable measure of attachment insecurity in patients with advanced cancer and can be recommended as a tool for clinical care and further research.

DOI: 10.1016/j.jpainsymman.2017.07.026

PMID: 28716619 [Indexed for MEDLINE]

Updated: October 8, 2019

3. Engelmann D, Scheffold K, Friedrich M, Hartung TJ, Schulz-Kindermann F, Lordick F, Schilling G, Lo C, Rodin G, Mehnert A. Death-Related Anxiety in Patients With Advanced Cancer: Validation of the German Version of the Death and Dying Distress Scale. Journal of Pain and Symptom Management. 2016 Oct; 52(4):582-587. doi: 10.1016/j.jpainsymman.2016.07.002. Epub 2016 Aug 9.

ABSTRACT:

CONTEXT: Distress and anxiety about issues related to death and dying is commonly experienced in patients with advanced disease and a limited life expectancy.

OBJECTIVES: To evaluate the psychometric properties of the German version of the Death and Dying Distress Scale (DADDS-G) in advanced cancer patients.

METHODS: We recruited advanced patients with mixed tumor entities (Union for International Cancer Control [UICC] Stage III/IV) treated in two German University Medical Centers during their outpatient treatment. After testing a preliminary version of the state-of-the-art translated original Death and Dying Distress Scale, we analyzed the psychometric properties of the shortened nine-item adapted DADDS-G using validated instruments measuring distress, anxiety, depression, fear of progression, and quality of life.

RESULTS: We obtained complete questionnaires from 77 of 93 patients with advanced cancer (response rate: 83%). Participants were mostly married or cohabiting (75%), well-educated, and both sexes were almost equally represented (52% men; mean age 58 years, SD = 12). The total mean DADDS-G score was 13.3 (SD = 8.5). Patients reported to be most distressed by the feeling of being a burden to others. The exploratory factor analysis led to one factor that accounted for more than 59% of the variance. The DADDS-G's internal consistency was excellent with Cronbach alpha = 0.91. The confirmatory factor analysis demonstrated a very good model fit. Death-related anxiety was significantly associated with distress, depression, anxiety, fear of progression, and lower quality of life ($P < 0.001$).

CONCLUSION: Results provide further evidence that the DADDS-G is a valid and reliable instrument of high clinical relevance for use in patients with advanced cancer.

DOI: 10.1016/j.jpainsymman.2016.07.002

PMID: 27521283 [Indexed for MEDLINE]

4. Tong E, Deckert A, Gani N, Nissim R, Rydall A, Hales S, Rodin G, Lo C. The meaning of self-reported death anxiety in advanced cancer. Palliative Medicine. 2016 Sep; 30(8):772-9. doi: 10.1177/0269216316628780. Epub 2016 Feb 8.

ABSTRACT:

BACKGROUND: Death anxiety is important but understudied in palliative care. New self-report measurements have been developed, but their interpretation and clinical utility may not be evident.

AIM: To inform our understanding of death anxiety in patients with advanced cancer by exploring the relationship between this self-reported symptom and its clinical presentation.

DESIGN: Participants were part of a psychotherapy trial in advanced cancer. First therapy session transcripts were analyzed using interpretive description in patients reporting low, moderate, and high death anxiety on the Death and Dying Distress Scale (DADDS).

SETTING/PARTICIPANTS: A total of 16 participants (10 women and 6 men) with advanced or metastatic cancer were sampled from the Princess Margaret Cancer Centre, Toronto, Canada. Six participants reported low death anxiety scores (Death and Dying Distress Scale: 0-19), five moderate (Death and Dying Distress Scale: 20-50), and five high (Death and Dying Distress Scale: 51-75).

RESULTS: The low death anxiety group exhibited psychological readiness for death, or contrastingly, non-reflectiveness about death. The moderate group recognized the imminence of mortality, which impacted treatment decisions and future plans. Prior experience with death was discussed as raising the salience of mortality. The high group felt dominated by powerful emotions and could not make sense of their situation. Their distress was exacerbated by substantial relational concerns.

CONCLUSION: Self-reported death anxiety is affected by the awareness and ability to reflect on mortality. Death and Dying Distress Scale scores may facilitate exploration of this symptom as part of a clinical assessment and may serve to guide treatment approaches. Greater attention to death anxiety is consistent with and recommended by contemporary approaches to palliative care.

DOI: 10.1177/0269216316628780

PMID: 26857360 [Indexed for MEDLINE]

5. Hannon B, Dyck M, Pope A, Swami N, Banerjee S, Mak E, Bryson J, Rodin G, Ridley J, Lo C, Le LW, Zimmermann C. Modified Edmonton Symptom Assessment System including constipation and sleep: validation in outpatients with cancer. Journal of Pain and Symptom Management. 2015 May; 49(5):945-52. doi: 10.1016/j.jpainsymman.2014.10.013. Epub 2014 Dec 15.

ABSTRACT:

CONTEXT: The Edmonton Symptom Assessment System (ESAS) measures the severity of nine symptoms. Constipation and sleep disturbance are common in patients with cancer, but are not currently included in the ESAS.

OBJECTIVES: To validate the numerical rating scale (NRS) versions of ESAS and its revised version (ESAS-r), with the additional symptoms of constipation and sleep (CS), and to assess patient preference for either version.

METHODS: Outpatients with advanced cancer (N = 202) completed three assessments during a single clinic visit: ESAS-CS, and an added time window of "past 24 hours"; ESAS-r-CS, with a time window of "now" and symptom definitions; and the Memorial Symptom Assessment Scale (MSAS). Internal consistency was calculated using Cronbach's alpha. Paired t-tests compared ESAS-CS and ESAS-r-CS scores; these were correlated with MSAS using Spearman correlation coefficients. Test-retest reliability at 24 hours was assessed in 26 patients.

RESULTS: ESAS-CS and ESAS-r-CS total scores correlated well with total MSAS (Spearman's rho 0.62 and 0.64, respectively). Correlation of individual symptoms with MSAS symptoms ranged from 0.54-0.80 for ESAS-CS and 0.52-0.74 for ESAS-r-CS. Although participants preferred the ESAS-r-CS format (42.8% vs. 18.6%) because of greater clarity and understandability, the "past 24 hours" time window (52.8%) was favored over "now" (21.3%). Shortness of breath and nausea correlated better for the "past 24 hours" time window (0.8 and 0.72 vs. 0.74 and 0.64 in ESAS-r-CS, respectively). The 24-hour test-retest of the ESAS-CS demonstrated acceptable reliability (intraclass correlation coefficient = 0.69).

CONCLUSION: The ESAS-CS and ESAS-r-CS NRS versions are valid and reliable for measuring symptoms in this population of outpatients with advanced cancer. Although the ESAS-r-CS was preferred, patients favored the 24-hour time window of the ESAS-CS, which also may best characterize fluctuating symptoms.

DOI: 10.1016/j.jpainsymman.2014.10.013

PMID: 25523890 [Indexed for MEDLINE]

6. Krause S, Rydall A, Hales S, Rodin G, Lo C. Initial validation of the Death and Dying Distress Scale for the assessment of death anxiety in patients with advanced cancer.

Journal of Pain and Symptom Management. 2015 Jan; 49(1):126-34. doi:

10.1016/j.jpainsymman.2014.04.012. Epub 2014 May 28.

ABSTRACT:

CONTEXT: The experience of death anxiety in patients with advanced cancer has been understudied partly because of the lack of a tailored measure for this population. The Death and Dying Distress Scale (DADDS) was constructed to address this gap. Although an initial version of this instrument has shown promising psychometric properties, validation of the finalized version is needed.

OBJECTIVES: This study aims to validate the recent 15-item DADDS by examining its factor structure and construct validity.

METHODS: Sixty participants with advanced or metastatic cancer were recruited from the Princess Margaret Cancer Centre, University Health Network, Toronto, Canada, into a pilot trial of a psychological intervention. This article analyzes the baseline measures on death anxiety, depressive symptoms (Patient Health Questionnaire-9, Structured Clinical Interview for Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition, Text Revision, Axis 1 Disorders), generalized anxiety (Generalized Anxiety Disorder-7), and preparation for end of life (Quality of Life at the End of Life-Cancer Scale). Exploratory factor analysis was conducted. Construct validity was assessed by correlations between measures.

RESULTS: Factor analysis revealed a dominant single factor explaining more than 75% of the shared variation between items. Factor loadings were high, ranging from 0.57 to 0.86. Item communalities were evenly ranged from 0.33 to 0.75 and with the 15:1 variable to factor ratio, suggest the viability of parameter estimates despite the small sample size. Cronbach's alpha was 0.95. Death anxiety was associated with less preparation for end of life ($r = -0.68$, $P < 0.0001$), more generalized anxiety ($r = 0.63$, $P < 0.0001$), and more depressive symptom severity ($r = 0.50$, $P < 0.0001$). Individuals with major depression had greater death anxiety than the nondepressed (mean difference = 17; 95% CI = 1.5-33), as did individuals with minor depression (mean difference = 25; 95% CI = 10-41).

CONCLUSION: The DADDS is a valid measure of death anxiety in patients with advanced cancer. It may provide useful information in the assessment and treatment of distress in patients near the end of life.

DOI: 10.1016/j.jpainsymman.2014.04.012

PMID: 24878066 [Indexed for MEDLINE]

7. Neel C, Lo C, Rydall A, Hales S, Rodin G. Determinants of death anxiety in patients with advanced cancer. BMJ Supportive & Palliative Care. 2015 Dec; 5(4):373-80. doi:

10.1136/bmjspcare-2012-000420. Epub 2013 Aug 22.

ABSTRACT:

OBJECTIVE: To examine the presence of death anxiety in patients with advanced cancer and to identify the psychosocial and disease-related factors associated with it.

DESIGN: Cross-sectional analysis of baseline data from a phase 2 pilot intervention trial.

SETTING: Princess Margaret Cancer Centre, University Health Network, Toronto, Canada.

PARTICIPANTS: 60 adult outpatients with metastatic breast, endocrine, gastrointestinal, gynaecological, genitourinary and lung cancer.

MAIN OUTCOME MEASURE: Death anxiety, as measured by the Death and Dying Distress Scale (DADDS).

RESULTS: Thirty-two per cent of the sample reported death anxiety of at least moderate severity. The most distressing concern involved fears about the impact of one's death on others, and the least distressing concerns were related to dying alone or suddenly. According to regression analyses, death anxiety was negatively associated with self-esteem, $b = -1.73$, CI 0.95 (-2.57 to -0.90) and positively associated with physical symptom burden, $b = 1.38$, CI 0.95 (0.44 to 2.31), having children under 18 years of age in the family, $b = 13.3$, CI 0.95 (2.15 to 24.5), and age,

Updated: October 8, 2019

b=0.40, CI0.95 (0.0023 to 0.79). The physical symptoms most strongly associated with death anxiety were changes in physical appearance, b=18.8, CI0.95 (8.21 to 29.5), and pain, b=10.1, CI0.95 (0.73 to 19.5).

CONCLUSIONS: The findings suggest that death anxiety in patients with advanced cancer is common and determined by the interaction of individual factors, family circumstances and physical suffering. Multidimensional interventions that take into account these and other factors may be most likely to be effective to alleviate this death-related distress.

DOI: 10.1136/bmjspcare-2012-000420

PMID: 24644177 [Indexed for MEDLINE]

8. Bagha SM, Macedo A, Jacks LM, Lo C, Zimmermann C, Rodin G, Li M. The utility of the Edmonton Symptom Assessment System in screening for anxiety and depression.

European Journal of Cancer Care (Engl). 2013 Jan; 22(1):60-9. doi: 10.1111/j.1365-

2354.2012.01369.x. Epub 2012 Jun 14.

ABSTRACT:

The Edmonton Symptom Assessment System (ESAS) is a common screening tool in cancer, although its validity for distress screening is unproven. Here, screening performance of the ESAS anxiety (ESAS-A) and depression (ESAS-D) items were validated against the anxiety [Generalised Anxiety Disorder-7 (GAD-7)] and depression [Patient Health Questionnaire-9 (PHQ-9)] subscales of the PHQ. A total of 1215 cancer patients completed the Distress Assessment and Response Tool (DART), a computerised distress screening instrument. Spearman's rank correlation coefficients and receiver operating characteristic curve analyses were used to evaluate the ability of ESAS-A and ESAS-D to identify moderate distress (GAD-7/PHQ-9 \geq 10). Spearman's rank correlation coefficients comparing ESAS-A and ESAS-D with GAD-7 and PHQ-9 were 0.74 and 0.72 respectively. Areas under the receiver operating characteristic curves were 0.89 and 0.88 for anxiety and depression respectively. A cut-off of \geq 3 on ESAS-A demonstrated a sensitivity of 0.91, specificity of 0.68, positive predictive value of 0.34 and negative predictive value of 0.97. A cut-off of \geq 2 on the ESAS-D demonstrated a sensitivity of 0.86, specificity of 0.72, positive predictive value of 0.46 and negative predictive value of 0.95. High sensitivities of ESAS-A and ESAS-D at certain cut-offs suggest they have use in ruling-out distress. However, their low specificities indicate secondary screening is needed to rule-in anxiety or depression for case-finding.

DOI: 10.1111/j.1365-2354.2012.01369.x

PMID: 22694595 [Indexed for MEDLINE]

9. Lo C(1), Hales S, Zimmermann C, Gagliese L, Rydall A, Rodin G. Measuring death-related anxiety in advanced cancer: preliminary psychometrics of the Death and Dying Distress Scale. Journal of Pediatric Hematology/Oncology. 2011 Oct; 33 Suppl 2:S140-5. doi: 10.1097/MPH.0b013e318230e1fd.

ABSTRACT:

The alleviation of distress associated with death and dying is a central goal of palliative care, despite the lack of routine measurement of this outcome. In this study, we introduce the Death and Dying Distress Scale (DADDS), a new, brief measure we have developed to assess death-related anxiety in advanced cancer and other palliative populations. We describe its preliminary psychometrics based on a sample of 33 patients with advanced or metastatic cancer. The DADDS broadly captures distress about the loss of time and opportunity, the process of death and dying, and its impact on others. The initial version of the scale has a one-factor structure and

Updated: October 8, 2019

good internal reliability. Dying and death-related distress was positively associated with depression and negatively associated with spiritual, emotional, physical, and functional well-being, providing early evidence of construct validity. This distress was relatively common, with 45% of the sample scoring in the upper reaches of the scale, suggesting that the DADDS may be a relevant outcome for palliative intervention. We conclude by presenting a revised 15-item version of the scale for further study in advanced cancer and other palliative populations.

DOI: 10.1097/MPH.0b013e318230e1fd

PMID: 21952572 [Indexed for MEDLINE]

10. Lo C, Burman D, Swami N, Gagliese L, Rodin G, Zimmermann C. Validation of the QUAL-EC for assessing quality of life in patients with advanced cancer. *European Journal of Cancer*. 2011 Mar; 47(4):554-60. doi: 10.1016/j.ejca.2010.10.027. Epub 2010 Dec 1.

ABSTRACT:

OBJECTIVE: Improving quality of life is the main goal of palliative cancer care. However, there is a lack of measures validated specifically for advanced cancer. The purpose of this study was to validate the Quality of Life at the End of Life (QUAL-E) measure in a sample of patients with advanced cancer.

METHODS: Data were analysed for 464 patients with advanced cancer who were participating in a randomised controlled trial of early palliative care intervention versus routine care. Patients completed the 26-item QUAL-E, the Functional Assessment of Cancer Therapy (FACT-G) quality of life measure and measures of spiritual well-being, performance status, symptom burden, satisfaction with care and communication with health care providers. We conducted a confirmatory factor analysis on the QUAL-E to test for the hypothesized four-factor structure and examined construct validity by calculating correlations with relevant scales.

RESULTS: A 17-item reduced version of the QUAL-E, the QUAL-E-Cancer (QUAL-EC) achieved an acceptable fit to a four-factor model. Both the full and reduced versions of the QUAL-E were internally reliable and showed good construct validity. Symptom Control was correlated with other measures of physical functioning; Relationship with Healthcare Provider was correlated with satisfaction with care and better physician and nurse communication; Preparation for End of Life was strongly associated with emotional well-being; and Life Completion was strongly associated with social and spiritual well-being.

CONCLUSIONS: Due to its good factor structure and sound psychometrics, we recommend the reduced QUAL-EC scale to assess quality of life in patients with advanced cancer.

DOI: 10.1016/j.ejca.2010.10.027

PMID: 21126869 [Indexed for MEDLINE]

11. Lo C, Walsh A, Mikulincer M, Gagliese L, Zimmermann C, Rodin G. Measuring attachment security in patients with advanced cancer: psychometric properties of a modified and brief Experiences in Close Relationships scale. *Psychooncology*. 2009 May; 18(5):490-9. doi: 10.1002/pon.1417.

ABSTRACT:

OBJECTIVE: Attachment security has been identified as an important buffer of distress in patients with cancer and other medical illnesses but current measures have not been adapted for this population who may be older, in long-term stable relationships, and suffering from considerable disease burden. This study reports on (1) the psychometric properties of a modified 36-item Experiences in Close Relationships scale (ECR), adapted for this population; and (2) the validity of a brief 16-item version of our modified scale.

METHODS: A modified ECR (ECR-M36) was constructed by rephrasing relevant items to refer more generally to people with whom one feels close, instead of specifically in relation to one's

Updated: October 8, 2019

romantic partner(s). Patients with metastatic gastrointestinal (GI) and lung cancer completed the ECR-M36 and other scales tapping self-esteem, social support, and depressive symptoms on two occasions within a period of 4-6 months. Based on factor analyses of the ECR-M36, 16 items were selected to form a brief measure (ECR-M16).

RESULTS: Factor analyses of both ECR forms revealed a higher-order factor structure in which four first-order factors (Worrying about Relationships, Frustration about Unavailability, Discomfort with Closeness, Turning Away from Others) loaded onto two second-order factors tapping Attachment Anxiety and Avoidance. Both ECR forms were reliable and valid.

CONCLUSION: The ECR-M36 and ECR-M16 are good measures of attachment orientations for use with medically ill, older populations.

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