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This is the final peer-reviewed author's accepted manuscript (postprint) of the following publication:

Published Version:

Piredda M., Candela M.L., Marchetti A., Biagioli V., Facchinetti G., Gambale G., et al. (2021). Development and psychometric testing of the care dependence perception questionnaire. EUROPEAN JOURNAL OF CANCER CARE, 30(4), 1-8 [10.1111/ecc.13430].

Availability:

This version is available at: https://hdl.handle.net/11585/965997 since: 2024-07-05

Published:

DOI: http://doi.org/10.1111/ecc.13430

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Development and psychometric testing of the Care Dependence Perception questionnaire Abstract

Objective This multicentre study aimed to develop a measure of the perception of care dependence in patients diagnosed with cancer, and to test its psychometric properties.

Methods The questionnaire was developed based on findings emerged from a metasynthesis and from qualitative studies conducted in three hospitals in Italy. The draft questionnaire was tested for face and content validity and pilot-tested with patients. The questionnaire was completed by caredependent patients with cancer. Test-retest was conducted to verify stability. Exploratory factor analysis (EFA) was performed using a Maximum Likelihood robust estimator.

Results and Conclusion The Scale-Content Validity Index was 0.92. The final 15-item questionnaire was completed by 208 patients admitted to two hospitals. The EFA yielded a two-factor model including a positive and a negative perception of care dependence. Factor score determinacy coefficients, Cronbach's alpha coefficients and Intraclass Correlations Coefficients yielded satisfactory results confirming internal consistency and stability. The hedonic balance score is also available as a single indicator of subjective well-being. The study provides initial validation of the Care DEeP Questionnaire that can be used by cancer nurses to assess positive and negative patient experiences with care dependence and to personalize and improve their care.

Keywords: Psychometrics, Surveys and Questionnaires, Statistical Factor Analysis, Nursing, Neoplasms, Care Dependence.

Introduction

Recent medical diagnostic and therapeutic advances have contributed to improving cancer survival and reducing mortality (Miller et al., 2019). However, the global incidence of cancer exceeded 18 million cases in 2018 and it is estimated to rise to more than 29 million new cases in 2040 (Ferlay et al., 2015; WHO, 2018) partly as a consequence of the ageing population (Menyhárt et al., 2018; Estapé, 2018). In addition, patients with cancer are often suffering from comorbidities and disabilities (Sarfati et al., 2016), which can contribute to their becoming dependent on care for the activities of daily life (Lage et al 2019).

Dependence on others from birth to death and vulnerability are inherent in human nature due to our bodily condition and relational being (Cestari et al., 2020). Illness, physical impairments or old age can increase and highlight this innate dependence, which is inevitable (Kittay 2011). However, prevailing western societal values might create expectations for individuals to be fully independent, self-sufficient, and able to play productive roles in society (Jones, 2015). For this reason, being dependent on others can be stigmatized, considered as a shameful condition implying lack of humanity rather than inherent in human nature (Jones, 2015).

This has also an impact on patients who experience nursing care dependence, which is associated with feeling useless, worthless (Eriksson and Andershed, 2008), and distressed by being a burden to others (Chindaprasirt et al., 2019). Patients' experiences are highly influenced by the type of nursing care received: positive care relationships can foster personal development and lead patients to find new balances, while negative care relationships can worsen helplessness and suffering (Piredda et al., 2015). In particular, patients with advanced cancer who became care dependent judged their condition as positive at times, and as negative at other times. Those who experienced care dependence as a positive or natural condition considered themselves privileged for being gifted with human richness through the people they met (Piredda et al., 2016). Furthermore, nurses taking care of patients with advanced cancer in palliative care underlined the role of the nurse-patient

relationship in positively or negatively influencing the patients' condition of dependence (Piredda et al., 2019).

Assessment of how dependence is perceived by patients with cancer would enable nurses caring for them to better meet their needs. For instance, nurses taking care of patients who are experiencing their care dependence negatively could plan appropriate strategies, such as discussing with patients how to deal with their situation and improving the nurse-patient relationship. A number of instruments are available to measure patient' functional independence in the activities of daily life, such as the Barthel Index, the Functional Independence Measure, and the Katz Index of Activities of Daily Living (Roedl et al., 2016). A specific measure of nursing care dependence (Care Dependence Scale, CDS) was developed based on the Henderson's model including not only functional, but also psychosocial and spiritual fundamental needs (Dijkstra et al., 1999). Although the CDS comprehensively assess the patient's care dependence in all human needs, it provides only a measure of the level of dependence. To our knowledge, no instrument is available to assess the patients' perceptions and experience of care dependence. Therefore, the aim of this study was to develop a questionnaire to assess the perception of care dependence in patients diagnosed with cancer, and to test its psychometric properties (in particular face, content and construct validity, and reliability in terms of internal consistency and stability).

Methods

Design

This was a multicentre cross-sectional validation study. In the first phase a questionnaire was developed and in the second phase it was administered to care-dependent hospital inpatients diagnosed with cancer. The guidelines of the European Statistical System for instrument development and validation were followed (Brancato et al., 2006). These included five steps: (1) conceptualization, (2) questionnaire design, (3) questionnaire testing, (4) revision and (5) data

collection. The first four steps were conducted during Phase 1 and the last step was conducted during Phase 2.

Phase 1: Development of the Questionnaire

Conceptualization. The definition of care dependence used in this study was that of the condition of patients whose self-care abilities have decreased and whose care requirements make them dependent on nursing care (Dijkstra et al., 1999). The theoretical framework used to develop the indicators came from a meta-synthesis of patients' perceptions of care dependence (Piredda et al., 2015) and from qualitative studies conducted with patients with cancer admitted to hospitals in three cities located in central and northern Italy (Candela et al., 2020, Piredda et al., 2016). From the above findings, patients' positive or negative perspectives of care dependence emerged.

Questionnaire design. A pool of 63 items was generated from the above qualitative data referring to negative (such as anger, guilt, sadness and shame) and positive (joy, serenity) emotions that could be felt in care dependence. To verify face validity, three meetings were held with a panel of experts including 2 methodologists, 4 oncology nurses, 2 nurse researchers and 1 clinical psychologist, to select and refine the items, reducing them to 25. The items consisted of positively or negatively worded statements; respondents would be asked to rate the extent to which they agreed with them on a 5-point Likert scale ranging from 1 (disagree) to 5 (totally agree).

Questionnaire testing and revision. To evaluate content validity, the items were rated for relevance and clarity by five oncology nurses using a 4-point Likert scale from 1 (not relevant) to 4 (highly relevant). Ten out of the 25 items did not achieve adequate I-CVI (Item-Content Validity Index) (>0.78) (Almanasreh et al., 2018) and were eliminated. The S-CVI (Scale-Content Validity Index) of the resulting 15-item version of the scale was 0.92 and the CVIs ranged from 0.8 to 1 (Almanasreh et al., 2018). Pre-field (observational and cognitive interview) and field (behaviour coding scheme and respondent debriefing) tests of the questionnaire draft were conducted with inpatients in the leading centre. The observational and cognitive interviews were conducted by two clinical psychologists with nine patients selected to maximize heterogeneity. The cognitive interviews included retrospective thinking aloud, retrospective probing, paraphrasing, and evaluation of the response latency. The response format was changed after some difficulties encountered during these tests. Pre-field tests were repeated with four further patients, yielding satisfactory results. The behaviour coding scheme and respondent debriefing (Johnson et al, 2018) were conducted with five inpatients of the leading centre, who did not have any difficulty in understanding the items; therefore the questionnaire was not changed further. The final draft was named "Care DEeP (DEpendence Perception) Questionnaire" and consisted of 15 items, 8 of which were indicators of negative perceptions and 7 of positive ones, positing a two-factor model.

Phase 2: Validation of the Questionnaire

Data collection. A convenience sample of patients admitted to two hospitals in Rome, Italy, were recruited, if they were: (a) aged ≥ 18 ; (b) diagnosed with cancer; (c) dependent on nursing care (as demonstrated by a score < 68 on the Italian version of the Care Dependency Scale – CDS, with lower scores indicating higher care dependence (Dijkstra et al., 1999); (d) able to understand and speak Italian. Exclusion criteria were the presence of cognitive impairment. In a convenience subset of patients the questionnaire was re-administered 4-6 days after the first administration (test-retest) to evaluate stability. This timeframe was used to warrant that the condition of dependence had not changed substantially, and that both administrations were completed during patient's admission, considering that mean length of stay in an oncology ward in Italy is 8.4 days (Eurostat, 2020). After completing the first test the patients were asked for consent to complete a second one. A code was applied to the first test to allow matching it to retest.

Ethics The study was conducted in accordance with the standards of good clinical practice and following the Helsinki Declaration (WMA, 2013). Approval for the study was obtained from the Ethics Committee of the leading centre [protocol number (REDACTED)] and the other participating

centres before starting. Research assistants provided eligible patients with written and oral information about the objectives and the methods of the study. They assured patients that their participation in the study would be voluntary and that they could withdraw consent at any time. It was made clear that the data collected would be kept confidential, in accordance with current law. Written informed consent was obtained from consenting participants.

Data analysis. Descriptive statistics were calculated for socio-demographic and clinical variables. Skewness and kurtosis indices were calculated to determine the normality of the item distribution. In order to test the scale dimensionality, an exploratory factor analysis (EFA) was performed, using the MLr estimator of Mplus that considers the non-normal distribution of data. Data factoriability was preliminarily ascertained through the Keiser Meyer Olkin (KMO) index of sampling adequacy and the Bartlett's test of spheriticy. KMO should be ≥ 0.60 to be acceptable (values ≥ 0.8 are adequate) and the Bartlett's Test of Sphericity should be significant to proceed with factor analysis (Brown 2015). To identify the number of factors to retain in the final solution multiple criteria were used: analysis of eigenvalues and of scree plot, factor simplicity (factor loadings > 0.30 and no cross-loadings), interpretability and theoretical sense. The fit of the model was tested using both omnibus fit indices, such as the chi-square (x^2) test (must be non significant), and incremental fit indices such as the Root Mean Square Error of Approximation (RMSEA [Steiger, 1990] values \leq 0.08 indicate a good fit), the Comparative Fit Index (CFI [Bentler, 1990] values \geq 0.90 indicate an acceptable fit), the Tucker and Lewis Index (TLI; values ≥ 0.90 indicate an acceptable fit) and the Standardized Root Mean Square Residual (SRMR [Hu and Bentler, 1999] values ≤ 0.08 indicate an acceptable fit) (Kline 2016).

The quality of the factors was further ascertained through the factor score determinacy coefficients Potential biases of their calculation were overcome by the use of MLr as parameter estimator (Beauducel and Hilger, 2017). Reliability in terms of internal consistency of the factors was analysed through Cronbach's Alpha Coefficient (values > 0.7 are considered adequate), and in terms of stability through the Intraclass Correlation Coefficient (ICC) performed using a two-way mixed effects model. Values of ICC 0.50-0.75 indicate moderate reliability, >0.75 indicate good reliability and \geq 0,9 indicate excellent reliability (Portney & Watkins, 1993; Polit & Beck, 2008). To estimate the precision of ICC, 95% confidence intervals (CI) were also computed. A sample of 17 subjects was required to reach an ICC 0.90 (95% CI + 0.1) with two repeated measures (De Vet et al., 2011).

Correlation between the mean scores of the resulting factors was evaluated by the Pearson Correlation Coefficient (two tailed). Significance was set at p < 0.05. The softwares SPSS 21.00 (IBM Corp, Chicago) and Mplus 6.1 (Muthén & Muthén Los Angeles, California 2012) were used for statistical analyses.

Results

Sample. Two hundred and nine patients participated in the study. One questionnaire was not completely filled out, and therefore 208 questionnaires were analysed. The sample included 97 (46.6%) male and 111 female (53.4%) cancer patients, with a mean age of 65.3 (SD 14.07, range 19-89) years. Participants were evenly distributed between the two hospitals, 42.8% of them had attended primary or secondary school, and 26% held a university degree. The most prevalent cancer diagnoses were sarcoma/bones (22.6%) and lung cancer (20.2%). The mean level of care dependence measured through the CDS was 43.54 (SD 7.27, range 25-62). More details of sample demographic and clinical characteristics are provided in Table 1.

TABLE 1 ABOUT HERE

Construct validity and reliability

The Bartlett's test of sphericity was significant ($\chi^2 = 870$, df = 105, P < 0.001) and the KMO index of sampling adequacy was 0.82. Therefore, the data set of the DEeP questionnaire was deemed suitable for a factor analysis. The item distribution did not approach univariate normality as some of the skewness and kurtosis indices were >|1| (Table 2).

TABLE 2 ABOUT HERE

Analysis of the first eigenvalues (4.304, 2.299, 1.095, 1.025, 0.925) supported a four-factor solution, while the scree-plot showed a sharp decrease of the slope after the third factor. However, the three- and four-factor solutions were not acceptable due to several items with unacceptable (<0.3 or >1) main loadings, and factors loaded by less than 3 items. The best solution found at the EFA was the two-factor model with the following fit indices: Chi-Square Test of Model Fit: (df: 76) = 154.731, p < 0.0001; RMSEA = 0.071 (90% CI 0.055 - 0.086); CFI = 0.883; SRMR = 0.049. All of the items showed loadings > 0.3, and significant p values < 0.05. Two items (Item 12 'I don't feel as a burden in depending on nurses' and item 14 'Being care dependent on nurses makes me feel uncomfortable') showed slight cross-loadings (Table 2). Factor 1, loaded by 7 items, was labelled *Positive perception* and Factor 2 was loaded by 8 items and was labelled *Negative perception*. The correlation between the two factors was -0.359. The total variance explained is 35.6% (15.3% for F1 and 20.3% for F2).

The factor score determinacy coefficients were 0.885 and 0.912, and the Cronbach's alpha coefficients were 0.755 and 0.795, respectively for *Positive perception* and for *Negative perception*. The ICC was r = 0.992 (95% CI: 0.977-0.997) for F1 and r = 0.980 (95% CI 0.944-0.993) for F2, both significant at p < 0.001.

Scores. The scores for the two factors were standardized to a range of 0-100. The mean scores were 82.83 (SD 15.30, range 31.4-100.0) for the *Positive perception* and 49.12 (SD 18.17, range 20-97.5) for the *Negative perception* factor (Table 3). As increasing values of the factors (negative and

positive) indicate increasing negative or positive perception of dependence, care dependence was perceived more positively than negatively in this sample. Mean scores for *Positive perception* were negatively correlated to those for *Negative perception* (r = -0.359, p < 0.001) and to the CDS score (r = -0.179· p < 0.001) (Table 3). Mean scores of both scales were not significantly different according to patients' age, sex or hospital. To obtain a synthetic indicator of subjective well-being, the hedonic balance (HB) score (Diener et al., 2009) was calculated by subtracting the total score of the *Negative perception* factor from the total score of the *Positive perception* factor (Allen et al., 2017). Hedonic balance was positive (HB =33.71, SD 27.65, range -66.07 to 80.00), indicating that patients reported higher scores for positive than for negative perceptions. The correlation between hedonic balance and CDS score was also positive (r = 0.138, p = 0.048) (Table 3).

TABLE 3 ABOUT HERE

Discussion

The study aimed to develop the Care DEeP Questionnaire to assess the perception of care dependence among inpatients diagnosed with cancer, and to preliminarily test its psychometric properties. This tool showed acceptable psychometric properties, suggesting that patients diagnosed with cancer could perceive their dependence on nursing care in a positive or negative way (Piredda et al., 2016). The Cronbach's alpha showed an acceptable reliability for both factors, and the ICC showed high stability over time.

The self-report Care DEeP Questionnaire can be used to measure the extent to which patients with cancer experience their dependence in a positive and/or negative way, and how much it impacts on their lives. The hedonic balance score, synthesizing the patients' perception of care dependence,

provides clinical oncology nurses with a single indicator of the patients' subjective well-being (Diener et al., 2009) regarding care dependence.

Such data are pivotal to planning individualized nursing care that goes beyond standard care, which is mainly aimed at promoting and restoring patients' independence (Alligood, 2017). For instance, cancer nurses caring for patients who report higher positive than negative perceptions of care dependence, aware that this is probably due to patients viewing nurses as lifelines (Candela et al., 2020), should not just focus on achieving patients' independence, since such patients could interpret this as abandonment. Instead, nurses should strive to build and foster significant interpersonal caring relationships both with patients perceiving dependence positively and with those perceiving it negatively. This will help nurses to deeply understand the patients' needs and to provide the support required through highly personalized and dignified care. Data gained through the DEeP questionnaire can raise nurses' awareness of dependent patients' emotional and relational needs, and guide them in planning and enacting strategies aimed at satisfying them. This can generate a virtuous circle, to improve both patients' and nurses' quality of life (Piredda et al., 2019).

In our sample the scores of "*Positive perception of care dependence*" were higher than those of "*Negative perception of care dependence*" and consequently, the resulting hedonic balance score was positive. These results confirm previous qualitative findings reporting positive experiences of care dependence in patients with cancer, who see the relationship with nurses as a lifeline (Candela et al., 2020). This positive view of dependence is also reported by patients who learn to appreciate the important aspects of life and to discover "the human richness of people" after becoming care dependent (Piredda et al., 2016).

The CDS score correlated negatively with *Negative perception* and positively with *Positive perception* and hedonic balance. This is not surprising, as higher CDS scores refer to lower grades of dependence, and one would expect patients to perceive the increase of care dependence more negatively and with less hedonic balance.

Limitations

A number of limitations should be acknowledged in this study. This is the first measure of patients' experiences and perceptions of care dependence: therefore, it was not possible to evaluate its concurrent validity through comparison with a gold-standard measure. Moreover, the fit indices of the EFA solution were not fully satisfactory and the sample size did not allow conducting both an exploratory and a confirmatory factor analysis. Further studies with bigger samples should confirm the dimensionality and construct validity of the new tool. Convergent and concurrent validity should also be evaluated in future studies as well as testing for measurement invariance. Stability was tested with a convenience sample and performed on a timeframe that could expose to recall of the previous responses. The instrument's stability should be further tested with randomized samples and longer time interval between assessments.

The sample included only patients with cancer admitted to acute care hospitals. Future research should test the psychometric properties of the Care DEeP Questionnaire with larger samples of patients in different settings, such as hospices or homecare to warrant greater generalisability.

Conclusions

This study provides cancer nurses with a new self-report tool that shows promising validity and reliability in patients with cancer in acute care. The Care DEeP Questionnaire could also be used to evaluate the impact on patients of positive or negative care relationships with nurses and to guide nurses towards implementing strategies to improve them, thus making a difference in the patients' care experiences. It can be filled in by patients upon admission, integrating it with CDS score: its use can contribute to gain a holistic view of the care dependent patients with cancer and to individualize care for them adding deeper knowledge of their lived experience.

Further research should culturally adapt and psychometrically test the Care DEeP Questionnaire in other countries in order to help understand how dependence is perceived by patients with cancer

trans-culturally. Finally, as chronic diseases other than cancer can also cause disabilities and care dependence, it could be interesting to develop similar instruments for use in other care-dependent populations.

References

- Allen, M.S., El-Cheikh, S., & Turner, M.J. (2017). A longitudinal investigation of irrational beliefs, hedonic balance and academic achievement. *Learning and Individual Differences*, 58, 41-45. doi: 10.1016/j.lindif.2017.07.003.
- 2) Alligood, M. R. (2017). Nursing theorists and their work-e-book. Elsevier Health Sciences
- Almanasreh, E., Moles, R., & Chen, T.F. (2018). Evaluation of methods used for estimating content validity. *Research in Social and Administrative Pharmacy*, Feb;15(2):214-221. doi: 10.1016/j.sapharm.2018.03.066.
- Beauducel, A. & Hilger, N. (2017). On the bias of factor score determinacy coefficients based on different estimation methods of the exploratory factor model, *Communications in Statistics -Simulation and Computation*, 46:8, 6144-6154. doi: 10.1080/03610918.2016.1197247.
- Bentler, P. M. (1990). Comparative fit indexes in structural models. *Psychological Bulletin*, 107(2), 238–246. doi:10.1037/0033-2909.107.2.238.
- 6) Brancato, G., Macchia, S., Murgia, M., Signore, M., Simeoni, G., Blanke, K., Hoffmeyer-Zlotnik, J. (2006). Handbook of recommended practices for questionnaire development and testing in the European statistical system. Retrieved from http://www.istat.it/en/files/2013/12/Handbook_questionnaire_development_2006.pdf.
- Brown, T. A. (2015). *Confirmatory factor analysis for applied research* (2nd ed.). New York: Guilford Publications.
- 8) Candela, M. L., Piredda, M., Marchetti, A., Facchinetti, G., Iacorossi, L., Capuzzo, M. T., Mecugni, D., Rasero, L., Matarese, M., & De Marinis, M. G. (2020). Finding meaning in life: an exploration on the experiences with dependence on care of patients with advanced cancer and nurses caring for them. *Supportive care in cancer: official journal of the Multinational Association of Supportive Care in Cancer*. Advance online publication. doi:10.1007/s00520-020-05300-8.

- Cestari, V., Moreira, T., Pessoa, V., Florêncio, R. S., Silva, M., & Torres, R. (2017). The essence of care in health vulnerability: a Heideggerian construction. *Revista brasileira de enfermagem*, 70(5), 1112–1116. https://doi.org/10.1590/0034-7167-2016-0570.
- 10) Chindaprasirt, J., Wongtirawit, N., Limpawattana, P., Srinonprasert, V., Manjavong, M., Chotmongkol, V., Pairojkul, S., & Sawanyawisuth, K. (2019). Perception of a "good death" in Thai patients with cancer and their relatives. *Heliyon*, 5(7), e02067. doi:10.1016/j.heliyon.2019.e02067.
- 11) De Vet, H. C., Terwee, C. B., Mokkink, L. B., & Knol, D. L. (2011). *Measurement in medicine: A practical guide*. Cambridge, England: Cambridge University Press.
- 12) Diener E. (2009) Subjective Well-Being. In: Diener E. (eds) *The Science of Well-Being. Social Indicators Research Series*, vol 37. Springer, Dordrecht.
- 13) Dijkstra, A., Buist, G., Moorer, P., & Dassen, T. (1999). Construct validity of the Nursing Care Dependency Scale. *Journal of Clinical Nursing*, 8(4), 380–388. doi:10.1046/j.1365-2702.1999.00245.x.
- 14) Eriksson, M., & Andershed, B. (2008). Care dependence: a struggle toward moments of respite.
 Clinical Nursing Research, 17(3), 220–236. doi:10.1177/1054773808320725.
- 15) Estapé, T. (2018). Cancer in the Elderly: Challenges and Barriers. Asia-Pacific Journal of Oncology Nursing, 5(1), 40–42. doi:10.4103/apjon.apjon_52_17.
- 16) Eurostat. Hospital discharges and length of stay statistics. Retrieved from: https://ec.europa.eu/eurostat/statisticsexplained/index.php/Hospital_discharges_and_length_of_stay_statistics#Hospital_discharges_b y_diagnosis
- 17) Ferlay, J., Soerjomataram, I., Dikshit, R., Eser, S., Mathers, C., Rebelo, M., Parkin, D.M., Forman, D., Bray, F. (2015). Cancer incidence and mortality worldwide: sources, methods and major patterns in GLOBOCAN 2012. *International journal of cancer*, 136(5), E359–E386. doi:10.1002/ijc.29210.

- 18) Hu, L. T., and Bentler, P. M. (1999). Cutoff criteria for fit indexes in covariance structure analysis: conventional criteria versus new alternatives. *Structural Equation Modeling: A Multidisciplinary Journal*. 6, 1–55. doi: 10.1080/10705519909540118.
- 19) Jones D. A. (2015). Human Dignity in Healthcare: A Virtue Ethics Approach. *The New bioethics: a multidisciplinary journal of biotechnology and the body*, 21(1), 87–97. https://doi.org/10.1179/2050287715z.00000000059.
- 20) Johnson, T., Pennel, B.E., Stoop, I., Dorer, B. (2018). Advances in Comparative Survey Methods. Wiley.
- 21) Kittay, E. F. (2011). The ethics of care, dependence, and disability. *Ratio Juris*, 24(1), 49–58. doi:10.1111/j.1467-9337.2010.00473.x.
- 22) Kline, R. B. (2016). *Principles and Practice of Structural Equation Modeling,4th Edn*. New York, NY: Guilford Press.
- 23) Lage, D., El-Jawahri, A. Fuh, C., Newcomb, R., Jackson, V., Greer, J., Temel, J.& Nipp, R. (2019). Functional impairment on admission and associated symptom burden and health outcomes among hospitalized patients with advanced cancer. *Journal of Clinical Oncology*. 37. 11554-11554. doi: 10.1200/JCO.2019.37.15_suppl.11554.
- 24) Menyhárt, O., Fekete, J. T., & Győrffy, B. (2018). Demographic shift disproportionately increases cancer burden in an aging nation: current and expected incidence and mortality in Hungary up to 2030. *Clinical Epidemiology*, 10, 1093–1108. doi:10.2147/CLEP.S155063.
- 25) Miller, K. D., Nogueira, L., Mariotto, A.B., Rowland, J.H., Yabroff, K.R., Alfano, C.M., Jemal, A.D.V.M., Kramer, J.L., & Siegel, R.L. (2019). Cancer treatment and survivorship statistics. *CA: A Cancer Journal for Clinicians*, 69, 363–385. doi:10.3322/caac.21565.
- 26) Muthén, L., & Muthén, B. (1998-2017). Mplus User's Guide: Statistical Analysis with Latent Variables (8th ed.). Los Angeles, CA: Muthén & Muthén.
- 27) Piredda, M., Bartiromo, C., Capuzzo, M. T., Matarese, M., & De Marinis, M.G. (2016). Nursing care dependence in the experiences of advanced cancer inpatients. *European Journal of*

Oncology Nursing: the Official Journal of European Oncology Nursing Society, 20, 125–132. doi:10.1016/j.ejon.2015.07.002.

- 28) Piredda, M., Candela, M.L., Mastroianni, C., Marchetti, A., D'Angelo, D., Lusignani, M.G., De Marinis, & Matarese, M. (2019). "Beyond the Boundaries of Care Dependence": A Phenomenological Study of the Experiences of Palliative Care Nurses. *Cancer nursing*, 10.1097/NCC.00000000000000701. Advance online publication.
- 29) Piredda, M., Matarese, M., Mastroianni, C., D'Angelo, D., Hammer, M. J., & De Marinis, M. G. (2015). Adult Patients' Experiences of Nursing Care Dependence. *Journal of nursing scholarship: an official publication of Sigma Theta Tau International Honor Society of Nursing*, 47(5), 397–406. doi:10.1111/jnu.12154.
- 30) Polit, D.F., Beck, C.T. (2008). *Nursing Research: Generating and Assessing Evidence for nursing practice, 8th ed.* Lippincott Williams & Wilkins, Philadelphia.
- 31) Portney, L. G., & Watkins, M. P. (1993). Foundations of clinical research: Applications to practice. Norwalk, Connecticut: Appleton and Lange.
- 32) Roedl, K.J., Wilson, L.S. and Fine, J. (2016). A systematic review and comparison of functional assessments of community-dwelling elderly patients. *Journal of the American Association of Nurse Practitioners*, 28, 160-169. doi:10.1002/2327-6924.
- 33) Sarfati, D., Koczwara, B., Jackson, C. (2016). The impact of comorbidity on cancer and its treatment CA: a cancer journal for clinicians, 66(4), 337–350. doi:10.3322/caac.21342.
- 34) Steiger, J. H. (1990). Structural Model Evaluation and Modification: An Interval Estimation
 Approach. *Multivariate Behavioral Research*, 25(2), 173–180.
 doi:10.1207/s15327906mbr2502_4.
- 35) World Health Organisation (2018). Estimated number of incident cases from 2018 to 2040, all cancers, both sexes, all ages. International Agency for Research on Cancer 2018. Retrieved from: <u>https://gco.iarc.fr/tomorrow/home.</u>
- 36) World Medical Association (2013). World Medical Association Declaration of Helsinki:

ethical principles for medical research involving human subjects. *JAMA*, 310(20), 2191–2194. doi:10.1001/jama.2013.281053.