Title: Contralateral Prophylactic Mastectomy (CPM) and the clinical consultation: A snapshot of UK healthcare professionals' views and experiences

Authors: Victoria Suzanne Williams[1], Philippa Tollow[1], Diana Harcourt[1], Ash Subramanian[2] and Nicole Paraskeva[1*]

Affiliations: **1** Centre for Appearance Research, University of the West of England, Bristol, UK

2 East Sussex Healthcare Trust, Conquest Hospital, The Ridge, Saint Leonards-On-Sea, UK

***Corresponding Author**

Abstract

Objectives: Increasing numbers of women are undergoing Contralateral Prophylactic Mastectomy (CPM) in the UK. However, professional guidelines suggest CPM does not offer oncological benefit to the majority of women with breast cancer. Whilst research has explored women's motivations for seeking CPM, the present study aimed to address a gap in the literature by investigating healthcare professionals' (HCP) experiences and attitudes of caring for women considering CPM.

Materials and Methods: HCPs involved in the care of women considering CPM were invited to complete an online survey concerning: the process and management of decision making, their attitudes towards CPM provision, and challenges they faced in CPM provision.

Results: Fifty-eight HCPs completed the survey. Respondents felt that perceived future breast cancer risk was women's most common motivation for CPM. 54% of respondents agreed patients should be offered the choice of CPM for risk-reduction if at increased clinical risk. 51% agreed patients should be offered the choice of CPM as a means of achieving symmetry, and 19% agreed that women should be offered CPM for reasons related to risk-reduction if they were *not* thought to be at an increased clinical risk. Patients' understanding of risks versus benefits was seen as the greatest challenge facing HCPs.

Conclusion: Many respondents were hesitant to explore CPM with all patients in their care, reflecting current service restrictions and their own beliefs around CPM. These findings highlight the need for exploration of patient's perspectives on this process and a review of care provision and information available related to CPM.

Keywords

Health professionals; surgery; breast cancer; contralateral prophylactic mastectomy; attitudes.

Introduction

The use of contralateral prophylactic mastectomy (CPM) following breast cancer has drawn considerable discussion and debate [1,2]. Rates of CPM are increasing in the UK [3], however, despite an increasing number of these operations taking place, professional guidelines currently recommend that CPM is not required by most women and may impact negatively on their quality of life [4]. Nevertheless, research suggests that women who have had CPM report high levels of decision satisfaction and psychological wellbeing [5].

Studies which have so far explored health professionals' views of CPM have reported a disparity in UK health professionals' attitudes towards the procedure and the subsequent support provided to women seeking it [6–8]. However, research has not yet examined when and how discussions about CPM might take place with patients, and what the barriers or challenges might be for health professionals regarding requests for the surgery. Given the increasing rates and uncertainty surrounding CPM, it was considered timely to gain a snapshot of healthcare professionals' views and experiences. This exploratory study aimed to investigate UK health professionals' perspectives on the process and management of women seeking CPM, their attitudes towards CPM, and their reflections on the challenges facing them when it is requested.

Materials and Methods

Design and materials

A 37-item survey was developed by the authors and made available for completion online by UK healthcare professionals involved in the management, treatment or care of women seeking and/or undergoing CPM. Participants were asked to provide demographics and practice details before completing sections related to process and management (e.g. 'what information do you provide to patients considering CPM?'), attitudes towards CPM (e.g. 'to what extent do you agree or disagree with the statement: 'patients should be offered the choice of CPM (with or without reconstruction) as a means of achieving symmetry'), and challenges related to CPM (e.g. 'what are the three greatest challenges related to CPM facing health professionals?'). The final section of the questionnaire, regarding challenges and CPM, was adapted from research exploring healthcare professionals' attitudes towards Ductal Carcinoma In Situ [9].

Participants and recruitment

Ethics approval was obtained from the first author's institution. Participants were required to be health professionals currently involved in the care of women considering or electing CPM in the UK. The study was promoted through relevant professional bodies, scientific meetings, and personal contacts. Participants were informed that all responses were confidential.

Statistical analyses

Statistical analyses were carried out using SPSS version 22. Content analysis was conducted by two researchers (the first and second authors) and Cohen's K was conducted to determine interrater reliability before a final decision about categories was made [10].

Results

Participants

This analysis is based on the responses of 58 healthcare professionals (64% female; mean age 47.4 years (range 25 – 72 years) who are involved in the care and management of women who are considering CPM . Thirty two identified as surgeons (55%), 21 as nurses (36%), two as psychologists (3%), one as a breast physician (2%), one as an onco-geneticist (2%) and one did not give their profession (2%). Mean time in their profession was 15.4 years (range 1–39 years) and they cared for an average of 9.6 patients undergoing CPM each year (range 1 – 45). All respondents worked in the UK (81% England, 12% Wales, 5% Scotland, 2% Northern Ireland) and the majority worked in the NHS (62% NHS, 9% private practice only, 29% both NHS and private practice).

Process and management

When asked about the treatment pathway for women seeking CPM, 40 respondents reported patients were discussed on a case-by-case basis in the multidisciplinary team meeting (69%), 37 reported patients had to attend an appointment with a breast care/specialist nurse (64%) and 31 reported patients had to see a psychologist/psychotherapist/counsellor (53%). Other processes reported by 11 respondents (19%) included genetic risk or family history risk assessment, discussion with surgeon, and clinical review in a reconstruction clinic. Three (5%) did not respond to this question.

When asked which patient groups were eligible for CPM in their service, 25 (43%) respondents reported 'all patients at high risk of future breast cancers' (e.g. BRCA carriers),

13 (22%) reported ‘all patients with above 30% lifetime risk’ (as highlighted in the Association of Breast Surgeons guidelines[2]), 6 (10%) reported ‘all patients who specifically requested CPM’, 3 (5%) reported ‘all patients with a large breast size not wanting reconstruction and wanting symmetry’, and one reported (2%) ‘all patients diagnosed with unilateral breast cancer’. Three respondents (5%) gave other reasons.

Nine respondents (16%) reported ‘always’ initiating CPM discussions with eligible patients, 43 (74%) ‘sometimes’ initiated this discussion, and 6 (10%) ‘never’ initiated this discussion but waited for eligible patients to raise the topic. Respondents were asked what factors determined whether they initiated discussions about CPM and, from a content analysis of 67 statements (from 39 respondents), the three most frequently reported factors were: high risk of further cancers (41.2%), patient wishes (14.7%), and breast size and symmetry (10.3%; see Figure 1). Cohen’s K showed a substantial level of inter-rater agreement initially, K = .943 ($p < 0.001$), 95% CI (0.850, 0.996), before any differences were discussed and agreed upon for final frequencies.

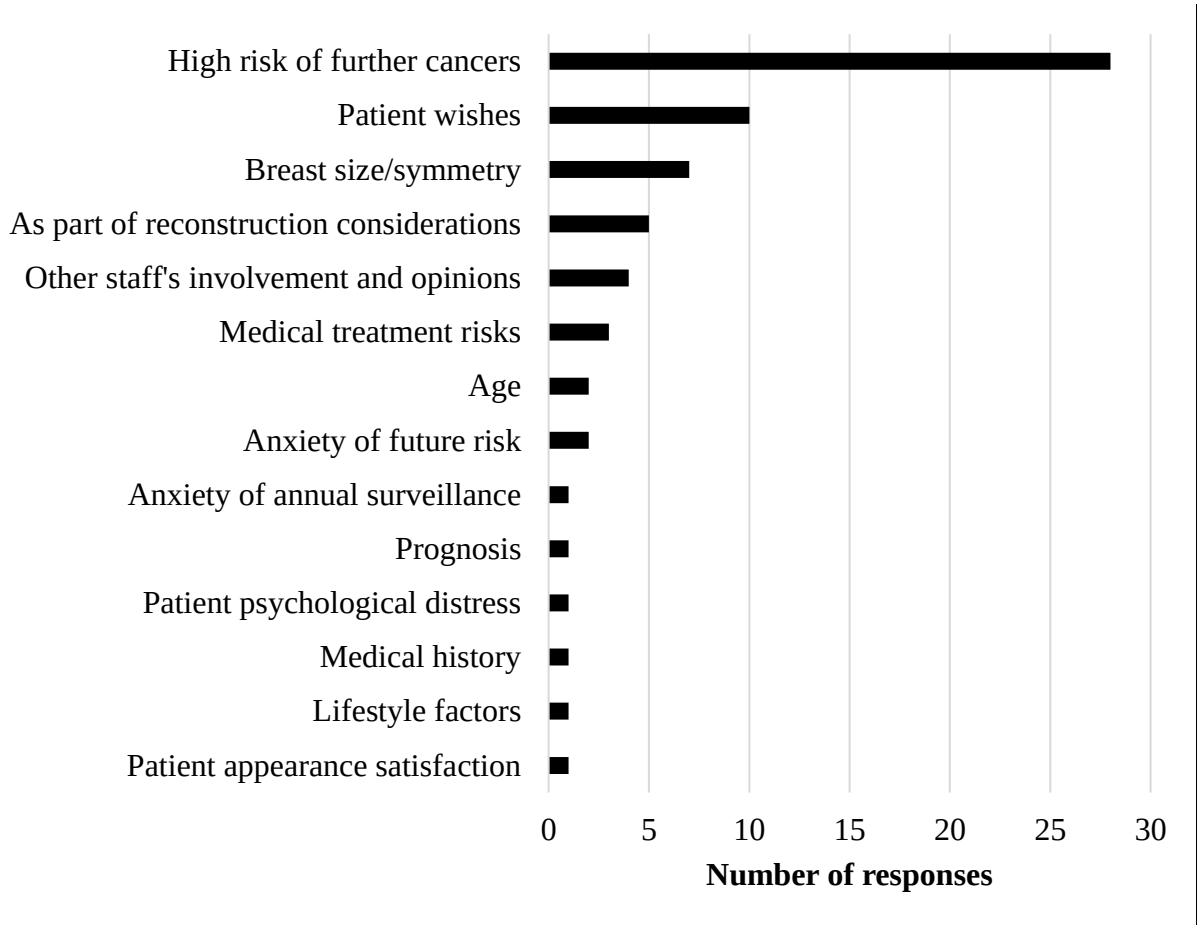

Figure 1. Factors determining whether health professionals initiate CPM discussions with eligible patients (n=39)

Respondents were asked what potential barriers prevented them from discussing CPM with patients. Thirty one respondents reported there were no potential barriers (53%), whilst 9 (16%) selected their colleagues' attitudes to CPM, 9 (16%) the increased risk of complications, 6 (10%) their own professional attitudes to CPM, 3 (5%) the lack of funding for the operation and 3 (5%) selected restrictions within their workplace. Seven participants (12%) selected 'other', and reported potential barriers including: eligibility, waiting list issues for non-cancer operations, and time. Five (9%) did not respond.

When asked whether they would be interested in learning more about how to facilitate clinical encounters concerning challenging CPM decision issues , 40 participants (80%) expressed an interest; suggesting they would prefer to do this in the form of an online training session (42%; n=31), written information (36%; n=26) or a face-to-face training session (33%; n=16).

Attitudes towards CPM

Health professionals felt that patients most commonly asked for CPM due to: perceived future breast cancer risk (reported by 84% of respondents; n=49), fear of future cancers not being detected by mammogram screening (66%; n=38), anxiety over annual screening and potential future diagnostic procedures (60%; n=35), cosmetic reasons (e.g. desire for symmetry; 59%; n=34), influence of family and friends (10%; n=6) and influence of partners/spouse (3%; n=2). Two (3%) participants gave additional reasons, including: desire to avoid further chemotherapy and the 'Angelina Jolie' effect. Three (5%) did not respond.

Most (94%; n=54) of respondents 'strongly' or 'somewhat' agreed that patients should be offered the choice of CPM for risk-reduction if they were at an increased clinical risk. Around half agreed it should be offered as a means of achieving symmetry (51%; n=30), and 11 (19%) supported it for reasons related to risk-reduction if they were *not* thought to be at an increased clinical risk. See Figure 2 for more detail.

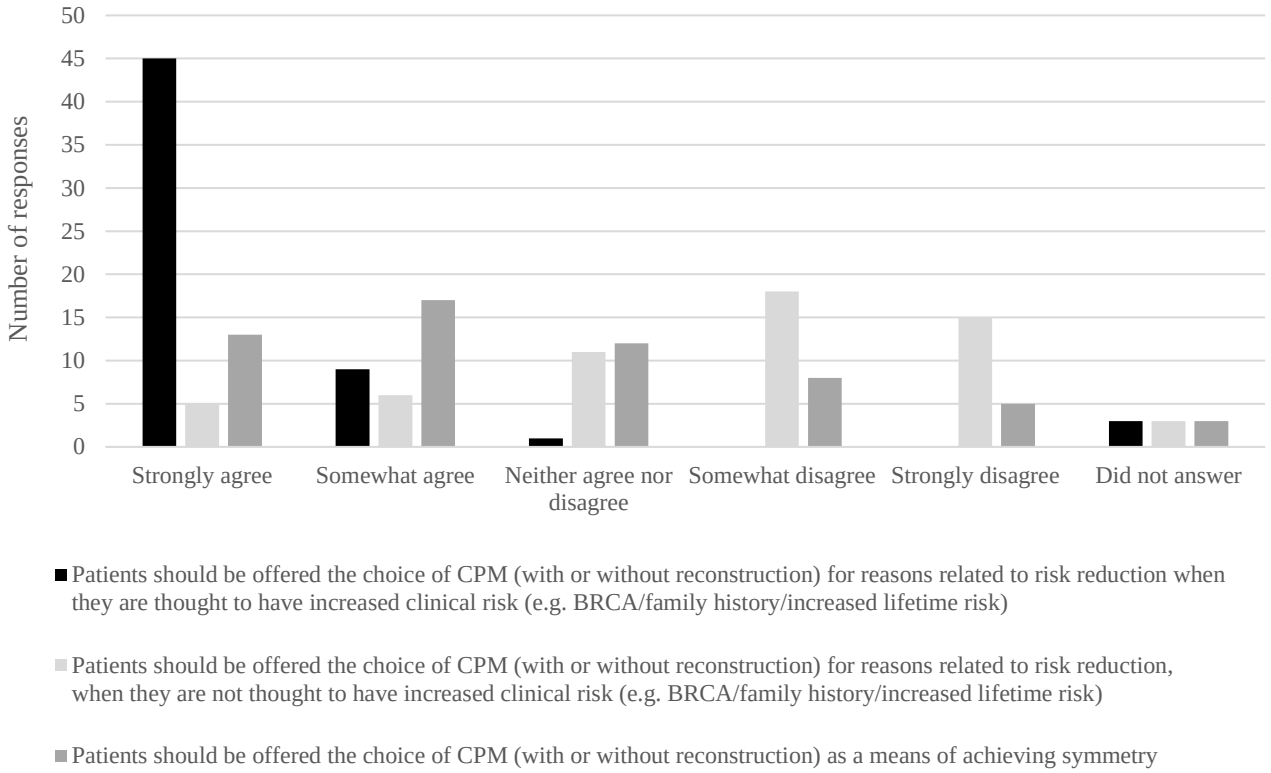

Figure 2. Health professionals' attitudes towards CPM provision (n=58)

Challenges related to CPM

Participants were asked to identify and rank the three greatest challenges facing healthcare professionals regarding CPM. A content analysis of 134 responses from 51 participants (see Figure 3) found that the most commonly reported challenge was patients' understanding of risks versus benefits (17.2%). Cohen's K showed a substantial level of inter-rater agreement before the researchers made a final agreement on analysis together, K = .943 ($p < 0.001$), 95% CI (0.902, 0.984).

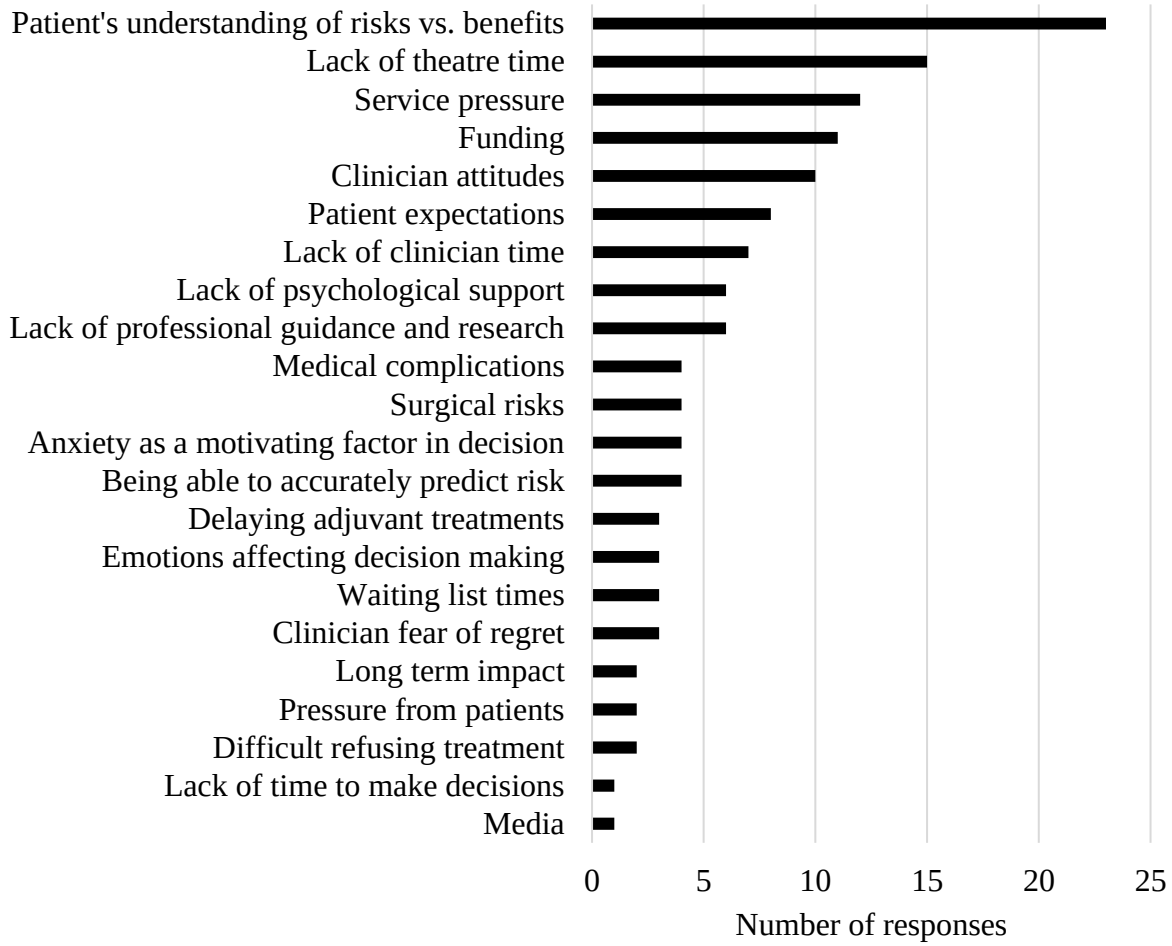

Figure 3. Frequency of issues reported as being the most challenging for health professionals when working with women seeking CPM (n=51)

Discussion

This survey explored health professionals' views and experiences regarding the provision of CPM and found that respondents' approaches to discussions about CPM varied widely. When asked about their attitude towards suitability for CPM, many clinicians in this study agreed that women requesting the surgery for reasons regarding symmetry and risk-reduction (when at an increased risk of future cancer) should be offered CPM, but felt it should not be offered to women who are not at high risk. This attitude is also reflected in the patient groups that respondents considered most eligible for CPM (i.e. patients at high risk of future breast cancers), and in respondents' reports of when they were more likely to initiate a conversation about CPM. These findings reflect current surgical guidelines [4] which recommend that women who do not have an increased risk of cancer should be discouraged from having CPM due to a lack of oncologic benefit.

Whilst many clinicians felt that 'concerns about future cancer risk when no increased clinical risk has been identified' were not an appropriate reason to offer CPM, they also reported that these concerns are among the most common reasons why women request it; demonstrating a disparity between health professionals' attitudes and women's motivations. In addition, whilst clinicians in this study suggested that one of their greatest challenges is patients' understanding of risk, research with women who are contemplating CPM suggests that many perceive any risk whatsoever to be intolerable [11]. It is possible that such disparities could present a challenge for the patient-clinician relationship and thus warrant further research which explores and compares clinician and patient perspectives. It may be the case that current guidance addresses risk reduction in an evidence-based fashion but places less importance on patient wishes when they do not have a medically acceptable level of risk but have equally strong personal reasons of their own. Clearly, a thorough understanding of the prognostic value of CPM is essential before embarking on this surgery but with this, personal choice must also feature highly.

Study limitations

Whilst this research has provided some insight into healthcare professionals' attitudes and experiences, respondents were all currently providing care for women considering CPM and thus it is possible that they were also more open to CPM as a treatment choice. It would be beneficial to understand the attitudes of other healthcare professionals working in breast

cancer, particularly those who do not offer CPM as a treatment choice. In addition, despite recruitment efforts, this survey includes only a relatively small sample of clinicians. Further research is required to explore the generalisability of these findings and determine whether there were any differences between professional, age or gender groups. A comparison of responses between breast surgeons and reconstructive breast plastic surgeons would be beneficial, as differing clinical priorities and considerations for surgical risks may determine treatment choices offered. Further research is needed to explore the patient experience of CPM.

Conclusions

This study found that health professionals can be hesitant to explore CPM with all mastectomy patients in their care, and that seeking CPM due to being at high risk of further cancer and for reasons associated with asymmetry are considered more legitimate than seeking it in response to fear of cancer when not at increased risk. The study highlights variations in healthcare professionals' views, and the need for further research to explore CPM from the patients' perspective and how health professionals working with women undergoing mastectomy might be supported with training and informational resources to aid discussions around CPM.

Acknowledgements

The authors would like to offer their thanks to the Association of Breast Surgery (ABS), British Association of Plastic Reconstructive and Aesthetic Surgeons (BAPRAS), and UK Oncological Nursing Society (UKONS) for sharing details of the survey with their members.

Funding

This project was funded by the Faculty of Health & Applied Sciences at the University of the West of England, Bristol and awarded to NP and DH.

NP, PT and DH are supported by Breast Cancer Now (grant no: 2014NovPR415).

Declaration of interest

None

References

[1] Boughey JC, Attai DJ, Chen SL, Cody HS, Dietz JR, Feldman SM, et al. Contralateral Prophylactic Mastectomy (CPM) Consensus Statement from the American Society of Breast Surgeons: Data on CPM Outcomes and Risks. Ann Surg Oncol 2016;23:3100–5. doi:10.1245/s10434-016-5443-5.

[2] Basu NN, Barr L, Ross GL, Evans DG, Surgery B, Hospital QE, et al. Contralateral Risk-Reducing Mastectomy : Review of Risk Factors and Risk-Reducing Strategies 2015;2015:8–14. doi:10.1155/2015/901046.

[3] Neuburger J, MacNeill F, Jeevan R, van der Meulen JHP, Cromwell DA. Trends in the use of bilateral mastectomy in England from 2002 to 2011: retrospective analysis of hospital episode statistics. BMJ Open 2013;3:e003179. doi:10.1136/bmjopen-2013-003179.

[4] Association of Breast Surgeons. ABS Summary Statement. Contralateral Mastectomy for Unilateral Breast Cancer. n.d.

[5] Collins K, Gee M, Clack A, Wyld L. The psychosocial impact of contralateral risk reducing mastectomy (CRRM) on women: A rapid review. Psychooncology 2017:1–10. doi:10.1002/pon.4448.

[6] Basu NN, Littlechild S, Barr L, Ross GL, Evans DG. Attitudes to contralateral risk reducing mastectomy among breast and plastic surgeons in England. Ann R Coll Surg Engl 2016;98:121–7. doi:10.1308/rcsann.2016.0039.

[7] Yi M, Hunt KK, Arun BK, Bedrosian I, Gutierrez Barrera A, Do K-A, et al. Factors affecting the decision of breast cancer patients to undergo contralateral prophylactic mastectomy. Cancer Prev Res 2010;3:1026–34.

[8] Musiello T, Bornhammar E, Saunders C. Breast surgeons' perceptions and attitudes towards contralateral prophylactic mastectomy. ANZ J Surg 2012;83.

[9] Kennedy F, Harcourt D, Rumsey N. Perceptions of ductal carcinoma in situ (DCIS) among UK health professionals. The Breast 2009;18:89–93. doi:10.1016/j.breast.2009.01.004.

[10] Cohen J. A coefficient of agreement for nominal scales. Educ Psychol Meas 1960;20:37–46.

[11] Beesley H, Holcombe C, Brown SL, Salmon P. Risk, worry and cosmesis in decision-making for contralateral risk-reducing mastectomy: Analysis of 60 consecutive cases in a specialist breast unit. Breast 2013;22:179–84. doi:10.1016/j.breast.2012.06.005.