

Running Head: Psycho-oncology Research in China

Title: A Systematic Review of Psycho-oncology Research in Chinese Populations:
Emerging Trends

Authors

Suzanne K. Chambers, PhD ¹⁻⁴†, suzanne.chambers@griffith.edu.au

Melissa K. Hyde, PhD ¹†, melissa.hyde@griffith.edu.au

Alma AU May-Lan, PhD ⁵§, alma.au@polyu.edu.hk

David Ip, PhD ⁵§, davidf.ip@inet.polyu.edu.hk

David Shum PhD ¹†, d.shum@griffith.edu.au

Jeff Dunn, PhD ^{1,2,6}* , jeffdunn@cancerqld.org.au

- 1 Griffith Health Institute, Griffith University, Australia
- 2 Cancer Research Centre, Cancer Council Queensland, Australia
- 3 Health and Wellness Institute, Edith Cowan University, Australia
- 4 Centre for Clinical Research, University of Queensland, Australia
- 5 The Hong Kong Polytechnic University, Hong Kong
- 6 School of Social Science, University of Queensland, Australia

Corresponding author:

Professor Suzanne Chambers

Professor of Preventative Health

Griffith Health Institute

Griffith University

Gold Coast Campus

QLD 4222

AUSTRALIA

Phone: + 61 7 5678 0008

Fax: + 61 7 5552 9081

E-Mail: suzanne.chambers@griffith.edu.au

Word Count: Abstract: 199; Text: 2500

Tables: 1

Figures: 5

Authors' disclosures of potential conflicts of interest: The author(s) indicated no potential conflicts of interest.

KEY WORDS: cancer, systematic review, psychological adjustment, quality of life, China

Acknowledgment to Lisa Herron for research assistance

† - Griffith Health Institute, Griffith University, Qld 4222 Australia

§ - Hong Kong Polytechnic University, Hung Hom, Kowloon, Hong Kong

*□ - Cancer Council Qld, PO Box 201, Spring Hill, Qld 4004, Australia

Abstract

The burden of cancer in China is increasing with future psycho-oncological interventions crucial. A systematic review of psycho-oncology research in China was undertaken to assess quantity, design and target trends over time. Medline, PsycINFO, CINAHL, ProQuest, Web of Science (1999 – November Week 4, 2012) were searched. Inclusion criteria were: included cancer patients and/or partners or caregivers from resident Chinese populations (either at least 80% of participants are from China, Hong Kong or Taiwan); assessed psychological adjustment relating to cancer and published in English after 1st January 1999 and prior to 30th November, 2012. In all, 208 articles met inclusion criteria. Of these: 52 were cross-sectional descriptive quantitative; 30 were cross-sectional descriptive qualitative; 27 were prospective descriptive quantitative; 2 were prospective descriptive qualitative; 18 assessed interventions; 79 presented instrument validation. Publications increased eightfold from 1999 to 2012. Most studies included patients (n=186) with 11 articles focussing on caregivers and two on patient-caregiver dyads. The most common cancer studied was breast cancer. The psycho-oncology research effort in China is dramatically increasing. A focus on culturally relevant approaches to underpin the evaluation of empirically derived interventions is warranted; as is direction of efforts to other cancers such as lung and prostate.

Introduction

In 2008 in China there were an estimated 2,895,162 new cases of cancer diagnosed, corresponding to an age-standardised incidence rate of 182.2 per 100,000 population; and almost 2 million people died from cancer with a mortality rate of 124.5 per 100,000 population (Ferlay, 2010), with cancer the second leading cause of death (Chen, 2008). In that same year, five-year prevalence for cancer was estimated to be 4,795,172, representing a crude rate of 440.5 per 100,000 population. The most common cancers for males were lung cancer (21.5%), stomach cancer (19.1%), liver cancer (18.0%), cancer of the oesophagus (10.7%) and colorectal cancer (7.9%). For females, the most common cancers were breast cancer (14.5%), lung cancer (14.1%), stomach cancer (12.2%), liver cancer (9.2%) and colorectal cancer (8.2%). Cancer is a major health concern for China now and into the future.

Specifically, as a result of economic development and lifestyle change, dramatic increases in breast cancer are predicted over the next ten years in this region; with some authors suggesting China is on the cusp of a breast cancer epidemic (Linos *et al.*, 2008). Similar increases are expected in lung cancer with China having a major impact on the worldwide burden of these two cancers over coming decades, with estimates of 1 million cases of lung cancer per year by 2025 (Zhao *et al.*, 2010) and 2.5 million cases of breast cancer by 2021 (Linos *et al.*, 2008). In the broader sense, a growing and aging population will increase the absolute numbers of people affected and the economic costs of this disease in this country (Zhao *et al.*, 2010). As cancer prevention programs in China are still in a very early stage of development (Zhao *et al.*, 2010), developing an evidence base about the best ways to provide psychological support to people affected by cancer in China is critical.

In this regard, directly translating knowledge about adjustment to cancer and effective psychological intervention from Western populations, that have a now considerable psycho-oncology tradition, into a Chinese context is likely inappropriate. Specifically, a person's

understanding of and responses to health and illness are grounded in the social and cultural milieu in which they live (Berger, 1998). Folk accounts of disease causation and progression; religious influences; as well as social norms and values influence the experience of cancer for the Chinese patient, family and community more broadly; and this in turn influences help seeking (Chen and Mak, 2008, Lin, 2002, Lui *et al.*, 2009) not only for cancer but also for mental health generally. At a more fundamental level, how emotions are expressed and valued also appears to differ by culture (Tsai *et al.*, 2006); and this includes the extent to which a culture is collectivist or individualistic (Eid and Diener, 2001); and the philosophical and religious traditions (e.g. Confucianism and Taoism) valued in that culture (Wallace and Shapiro, 2006). An indigenous Chinese body of psycho-oncological knowledge that is context sensitive is vital in the face of the growing cancer burden in China.

Accordingly, the aim of this study was to describe the quantum of psycho-oncology research in China; and trends over time in focus. From this, recommendations for a future psycho-oncology research agenda in China are proposed.

Method

Medline and PsycINFO, CINAHL, ProQuest, and Web of Science (1999 – November Week 4, 2012) were searched. In order to obtain a broad background picture of the amount of research activity in Asian countries and to reduce the chance of missing relevant articles, the first search included all Asian countries and this was focussed in to China as a last step. Accordingly, the following keywords and subject headings were used: Cancer.mp, metastasis.mp, malign\$.mp, adreno\$.mp, chemo\$.mp, neoplasm\$.mp, radio\$.mp, psychosocial.mp, well-being.mp, coping.mp, anxiety.mp, depression.mp, HRQoL.mp, survivor.mp, pain.mp, fatigue.mp, Asia\$.mp. China.mp, Chinese.mp, Hong Kong.mp, India\$.mp, Indonesia\$.mp, Japan\$.mp, Korea\$.mp, Phillipines.mp, Filipino.mp, Taiwan\$.mp, Thai\$.mp. To enhance the literature search, these terms were used in conjunction with searches aimed at identifying a comprehensive breadth of cancer-based research related to quality of life and psychological adjustment. For instance, “exp carcinoma/”, exp neoplasm\$, exp metastasis\$, “exp quality of life/”, “exp social adjustment” and “exp psychological adjustment/” were also searched. Potentially relevant articles were identified by examining the title and abstract and then retrieved for more detailed evaluation against the inclusion criteria by two reviewers (SC and MH). Both qualitative and quantitative studies were included. Editorials, books, dissertations, case reports, commentaries, systematic reviews, reviews, and meta-analyses were excluded.

Studies were selected for initial review if they met the following pre-determined inclusion criteria: Were published in English and included adult cancer patients and/or partners or caregivers who resided in Asia (either at least 80% of participants are from Asia and had/have cancer or were partners or caregivers of cancer patients); AND Described quality of life, health-related quality of life, or psychological and social adjustment of cancer patients in Asia; OR Compared quality of life, health-related quality of life, or psychological adjustment of cancer patients in Asia against healthy controls; OR assessed cancer related quality of life, cancer specific health-related quality of life, psychological and social

adjustment relating to cancer and included an outcome of interest – physical health, mental health, health utility, cancer specific distress; depression/anxiety severity, disability, mobility, physical activity, social activity, and health status. For final inclusion studies needed to have a psychological component as the principal focus.

Results

Search results

The process of identifying relevant articles for the review is outlined in Figure 1. The combined Medline and PsycINFO, CINAHL, ProQuest, and Web of Science database searches identified 1508 citations. On examination of titles and abstracts, 625 were potentially relevant and after further review 576 were retrieved for evaluation. As the focus of this review was psychological adjustment, research articles that focussed principally on quality of life, fatigue and pain and that did not include a psychological component were excluded leaving 407 articles that included all Asian countries (see Table 1 for breakdown of countries). In all, 208 articles that met all inclusion criteria and included Chinese participants were retained for review: 52 were cross-sectional descriptive quantitative designs; 30 were cross-sectional descriptive qualitative studies; 27 were prospective descriptive quantitative studies; 2 were prospective descriptive qualitative studies, 18 were intervention studies (12 randomised controlled trials, 5 experimental/quasi-experimental studies, 1 evaluation), and 79 were instrument validation studies.

Location, study type and focus and temporal trends

Of the Asian countries represented, most studies were conducted in China (including Hong Kong), Japan, and Taiwan (Table 1). For Chinese regions only, most studies were conducted in Taiwan (n = 78) and Hong Kong (n = 75); although the number of studies from China (n = 55) show an increase over time (Figure 2). Overall, the research outputs from Chinese regions increased over time approximately eightfold (Figure 3) with a comparison of the specific years 1999-2002 (n = 20) and 2009-2012 (n = 107) showing approximately a

fivefold increase in the number of studies. Regarding type of study, strong increases over time were evident for the number of studies to validate assessment measures; and to a lesser extent an increase in qualitative prospective research (Figure 4). An increase in intervention studies was also evident from 2010. However, a comparison of the number of qualitative descriptive (n = 5 vs. 15), quantitative descriptive (n = 7 vs. 46), intervention (n = 2 vs. 12), and instrument validation (n = 6 vs. 34) studies for the specific years 1999-2002 and 2009-2012, showed that proportionately the increases in each study type were not statistically significantly different ($\chi^2(3, N = 127) = 1.59, p = 0.66$). In all, studies from Chinese regions sampled predominantly patients (n=186) with only 11 articles focussing on caregivers and two on patient-caregiver dyads. Of these studies focussing on caregivers most were conducted in Taiwan and from 2007 onwards.

Figure 5 displays the number of studies for each cancer type. Overall, the most common single cancer type represented was breast cancer (20.7% of studies), followed by head and neck (7.2%) and gastro-intestinal (6.7%) cancers. 15.4% of studies did not focus on any one cancer type. Studies for the specific time periods 1999-2002 and 2009-2012 were compared to determine whether articles which focussed on a particular cancer type shifted over time to match the main cancer types for men and women in China in terms of incidence (men: lung, stomach, liver; women: breast, lung, stomach) and mortality (men: lung, liver, stomach; women: lung, stomach, liver) (Ferlay, 2010). This comparison showed only two studies in our review for 1999-2002 matching the main cancer types; 1 each for breast and lung cancer. In contrast, from 2009-2012, 30 studies focussed on breast cancer, 2 on lung cancer, 1 on stomach cancer, and 5 on liver cancer.

Discussion

Our review found an eightfold increase in the number of publications relating to psycho-oncology in Chinese regions from 1999 to 2012. In this regard, a recent review of psychology research trends internationally found a sixfold increase in China from 1996 to

2010, although the research effort internationally remained dominated by the United States (O'Gorman *et al.*, 2012). Wealth intensity (as measured by Gross Domestic Product) was found to be the major predictor of increases in research effort. Wealth likely reflects the extent to which the necessary infrastructure for such research has been developed (Arnett, 2008, Sánchez-Sosa and Riveros, 2007). As well, it has been suggested that the level of individualism–collectivism in the culture of a country may influence psychologically oriented research, given the focus of the individual in psychology generally (Jing, 2000, O'Gorman *et al.*, 2012). Finally, in developing countries where economic development may be the major national focus, psychology may be a second order issue compared to problems such as agriculture, housing and education (Jing, 2000). This may also be the case for psycho-oncology where the development of treatment facilities and cancer prevention programs may at this point take precedence or priority. However, the finding that psycho-oncology research has dramatically increased in quantum over the past decade in China suggests that this aspect of cancer care is gaining increasing focus in this region.

In this regard, national cancer control plans are a central element of ensuring that comprehensive cancer care is developed and available to populations with the aim of lowering cancer incidence and improving quality of life for cancer patients (World Health Organisation, 2013). Cancer prevention and control is a significant component of the *China National Plan for NCD Prevention and Treatment 2012-2015* currently being implemented (Chinese Centre for Disease Control and Prevention, 2013). The focus for cancer in this plan is on the early detection and treatment of cancers with high incidence and/or mortality in high-risk areas. While psychosocial care for cancer patients is not specifically mentioned in this plan, the need for rehabilitation guidance to reduce disability, promotion of self-management, and more counselling and “medical science information” for patients are described. Taiwan is presently implementing the *Second Phase Cancer Control Program Cancer Screening* (2010-2013), building on its *Five-Year National Cancer Control Program* (2005-2009) (Department of Health (R.O.C. Taiwan), 2012). The focus here is on expanding

cancer screening services to increase participation rates, with some attention to improving treatment and hospice care for people with cancer. In Hong Kong cancer prevention and control efforts are guided by the government's Cancer Coordinating Committee, established in 2001 (Hong Kong Legislative Council, 2012). From this one can conclude that a policy platform for a psycho-oncology research agenda does exist in China. With sufficient support, it could produce real gains in knowledge about the optimal approach to ameliorating the negative psychosocial and quality of life effects of a cancer diagnosis on patients and their families in this region.

While the increase in research quantum reflects a positive orientation towards psycho-oncology in this region, we did not observe a significant movement from descriptive studies towards intervention research, however the field may yet be still in a developmental phase. Specifically, the field will first need to develop appropriate measurement tools to provide a platform for longitudinal descriptive research before the ultimate goal of intervention and finally dissemination research can be achieved. With regards to the translation and validation of existing measurement tools and scales in other languages, it is important to note that the relevance of the constructs measured in tools developed in Western settings cannot be assumed to apply to Chinese populations. Unless the deep structure of the method applied is consonant with the culture in which it is applied, the meaning and impact of the research findings are questionable (Resnicow *et al.*, 1999). Addressing this question is outside of the scope of the present study, however this is a focus for future research review. Interestingly, a review of trends in quality of life research internationally also failed to find a significant shift towards intervention research (Bailey *et al.*, 2010). These researchers noted that descriptive research, by contrast to intervention research, is less expensive, time consuming, and requires less expertise. However, the failure to move towards intervention research over time was seen as a significant deficit in the quality of life research. While it would be premature to draw such conclusion from the present study with this specific

regional focus, our findings do highlight the need for Chinese psycho-oncology researchers to plan strategic movement towards culturally relevant multi-disciplinary intervention science.

The research identified in this review was predominantly focused on breast cancer patients, and this reflects trends in the broader literature in this area where breast cancer has consistently received more research attention (Sanson-Fisher *et al.*, 2009). Contrasting the spread of research activity with cancer incidence in China suggests that more attention than is currently evident needs to be directed to lung cancer patients (Guo *et al.*, 2012). In addition, prostate cancer is an emerging priority in China and Asia more broadly, with currently 14% of prostate cancer diagnoses worldwide occurring in the Asia Pacific, and almost one third of these will be in China (28%) (Baade *et al.*, 2012). To date, research examining the impact of prostate cancer on Chinese men is scant such that a greatly increased psycho-oncology research effort towards this area of focus is warranted (Chambers *et al.*, 2013).

The finding that carers and family members were infrequently included in this research seems surprising given the importance of filial connections in Chinese society (Tang *et al.*, 2007). This may in part relate to social norms about the extent to which cancer is 'discussable' in Chinese cultures. Lui *et al.* (2009) reported that in an Australian sample of Chinese migrants cancer was seen as a taboo subject in the community, and that having cancer was associated with social stigma (Lui *et al.*, 2009). This social stigma may relate to beliefs that cancer occurs as punishment or retribution for past misdeeds (Yeo *et al.*, 2005); is contagious (Huang *et al.*, 1999); or a sign of bad luck or bad spirits (Yeo *et al.*, 2005); In this setting, involving patients in research about the cancer experience as a first step, let alone family or close others who may also feel stigmatised, may be challenging. There is also a stigma associated with psychological ill health, emanating both from the individual themselves who may feel a failure to live up to social roles and responsibilities as a result of being ill; and from social views that those with mental illness are dangerous and

uncontrollable (Stewart *et al.*, 2010). Hence, stigma and the secrecy that follows it presents as a particular barrier to psycho-oncology research.

Conclusion

Psycho-oncology research is the platform for evidence-based psychosocial care for people affected by cancer. The psycho-oncology research effort in China is dramatically increasing, however attention to a defined research agenda that directs this effort may be warranted. In particular, an explicit focus on culturally relevant approaches; coordination of scale development to prevent duplication and to ensure salience to Chinese values and norms; clarity on not only the prevalence of distress but also the key domains of distress; and from this the development and assessment of empirically based interventions for those in most need are warranted. Building on, but not replicating, the psycho-oncology research approaches in Western countries in a planned and collaborative approach may be most efficacious.

References

- Arnett J. (2008) The neglected 95%. *The American Psychologist* **63**, 602-614.
- Baade P., Youlden D., Cramb S., Dunn J. & Gardiner R. (2012) Epidemiology of Prostate Cancer in the Asia-Pacific Region. **In Press**.
- Bailey L. J., Sanson-Fisher R., Aranda S., D'este C., Sharkey K. & Schofield P. (2010) Quality of life research: types of publication output over time for cancer patients, a systematic review. *European Journal of Cancer Care* **19**, 581-588.
- Berger J. T. (1998) Culture and ethnicity in clinical care. *Archives of Internal Medicine* **158**, 2085.
- Chambers S., Hyde M., Ip D., Dunn J. & Gardiner R. (2013) A systematic review of research into the psychological aspects of prostate cancer in Asia: What do we know? *Asian Pacific Journal of Cancer Prevention* **Accepted March 2013**.
- Chen S. X. & Mak W. W. (2008) Seeking professional help: Etiology beliefs about mental illness across cultures. *Journal of Counseling Psychology* **55**, 442-450.
- Chen Z. (2008) The Third National Death Cause Survey Report. . Beijing, China.
- Chinese Centre for Disease Control and Prevention (2013) China National Plan for NCD Prevention and Treatment (2012-2015). Ministry of Health, Beijing, People's Republic of China.
- Department of Health (R.O.C. Taiwan) (2012) Taiwan Public Health Report 2012. . Department of Health, R.O.C. (Taiwan), Taipei City, Taiwan.
- Eid M. & Diener E. (2001) Norms for experiencing emotions in different cultures: Inter-and international differences. *Journal of personality and social psychology* **81**, 869-885.
- Ferlay J., Shin, Hr, Bray, F, Forman, D, Mathers, C, and Parkin, Dm (2010). GLOBOCAN 2008 v1.2, Cancer Incidence and Mortality Worldwide: IARC CancerBase No 10. Available from: <http://globocan.iarc.fr> (cited 2010).
- Guo P., Huang Z., Yu P. & Li K. (2012) Trends in cancer mortality in China: an update. *Annals of Oncology* **23**, 2755-2762.

- Hong Kong Legislative Council (2012) Official Record of Proceedings of the Legislative Council, Wednesday 8 February 2012, (ed LEGISLATIVE COUNCIL), p. 5266. Hong Kong.
- Huang X., Butow P., Meiser B. & Goldstein D. (1999) Attitudes and information needs of Chinese migrant cancer patients and their relatives. *Australian and New Zealand journal of medicine* **29**, 207-213.
- Jing Q. (2000) International psychology. In: *International handbook of psychology* (eds. PAWLIK, K. & ROSENZWEIG, M.), pp. 570 - 584. Sage Publications, London, UK.
- Lin Y.-N. (2002) Taiwanese university students' perspectives on helping. *Counselling Psychology Quarterly* **15**, 47-58.
- Linos E., Spanos D., Rosner B. A., Linos K., Hesketh T., Qu J. D., Gao Y.-T., Zheng W. & Colditz G. A. (2008) Effects of Reproductive and Demographic Changes on Breast Cancer Incidence in China: A Modeling Analysis. *Journal of the National Cancer Institute* **100**, 1352-1360.
- Lui C.-W., Ip D. & Chui W. H. (2009) Ethnic Experience of Cancer: A Qualitative Study of Chinese–Australians in Brisbane, Queensland. *Social Work in Health Care* **48**, 14-37.
- O'gorman J., Shum D. H., Halford W. K. & Ogilvie J. (2012) World Trends in Psychological Research Output and Impact. *International Perspectives in Psychology: Research, Practice, and Consultation* **1**, 268-283.
- Resnicow K., Baranowski T., Ahluwalia J. & Braithwaite R. (1999) Cultural sensitivity in public health: defined and demystified. *Ethnicity & disease* **9**, 10.
- Sánchez-Sosa J. & Riveros A. (2007) Theory, research, and practice in psychology in the developing (majority) world. In: *Toward a global psychology: Theory, research, intervention, and pedagogy* (eds. Stevens, M. & Gielen, U.), pp. 101-146. Erlbaum, Mahwah, NJ.
- Sanson-Fisher R., Bailey L., Aranda S., D'este C., Stojanovski E., Sharkey K. & Schofield P. (2009) Quality of life research: is there a difference in output between the major cancer types? *European Journal of Cancer Care* **19**, 714-720.

- Stewart S. M., Lee P. W. H. & Tao R. (2010) Psychiatric disorders in the Chinese In: *The Oxford handbook of Chinese psychology* (ed. BOND, M. H.), pp. 367-382. Oxford University Press, Incorporated, New York.
- Tang S. T., Li C.-Y. & Liao Y.-C. (2007) Factors associated with depressive distress among Taiwanese family caregivers of cancer patients at the end of life. *Palliative medicine* **21**, 249-257.
- Tsai J. L., Knutson B. & Fung H. H. (2006) Cultural variation in affect valuation. *Journal of personality and social psychology* **90**, 288.
- Wallace B. A. & Shapiro S. L. (2006) Mental balance and well-being. *American Psychologist* **61**, 690-701.
- World Health Organisation (2013). Cancer: National cancer control programmes. Available from: <http://www.who.int/cancer/nccp/en/> (cited 2013).
- Yeo S. S., Meiser B., Barlow-Stewart K., Goldstein D., Tucker K. & Eisenbruch M. (2005) Understanding community beliefs of Chinese-Australians about cancer: Initial insights using an ethnographic approach. *Psycho-Oncology* **14**, 174-186.
- Zhao P., Dai M., Chen W. & Li N. (2010) Cancer Trends in China. *Japanese Journal of Clinical Oncology* **40**, 281-285.

Table 1. Countries Represented in Asian Psycho-oncology Articles Retrieved (n= 407)

Country	n
China (56)/Hong Kong (74)	130
Japan	82
Taiwan	78
India	31
Thailand	30
Korea	28
Singapore	12
Malaysia	7
Sri Lanka	4
Philippines	4
Indonesia	1

Figure 1: Final process of inclusion and exclusion of studies for the literature review

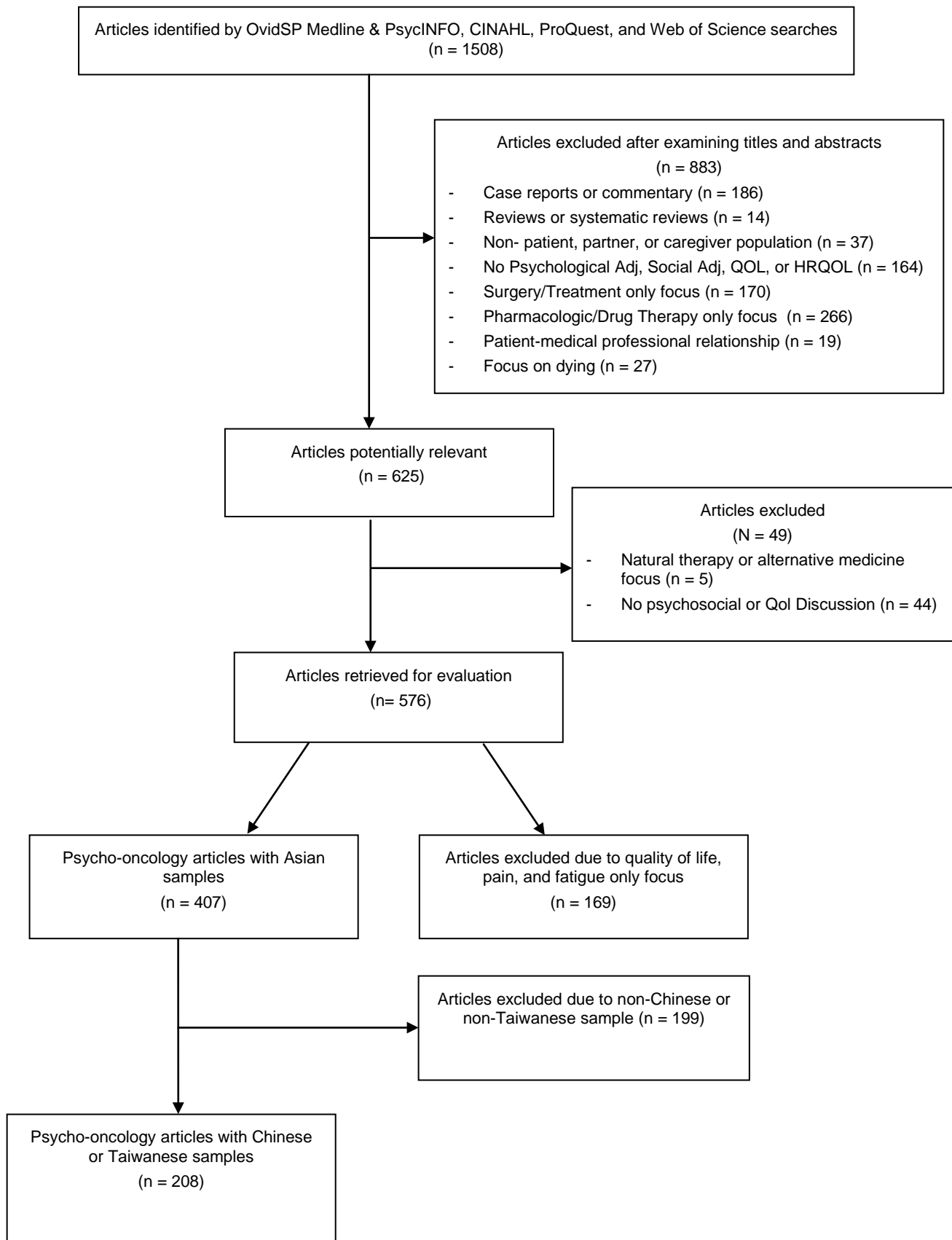


Figure 2. Country and trend over time for Psycho-oncology Articles in Chinese regions (n = 208)

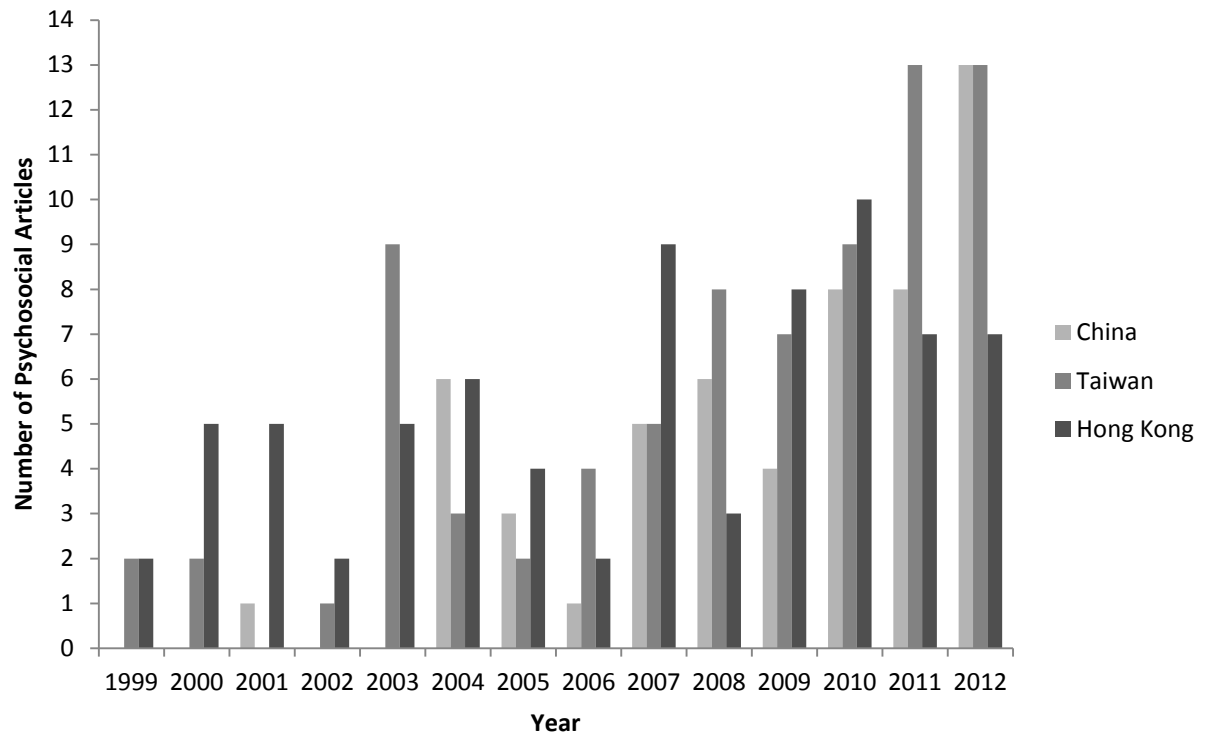


Figure 3. Trend in number of Psycho-oncology Articles in Chinese regions from 1999-2012 (n = 208)

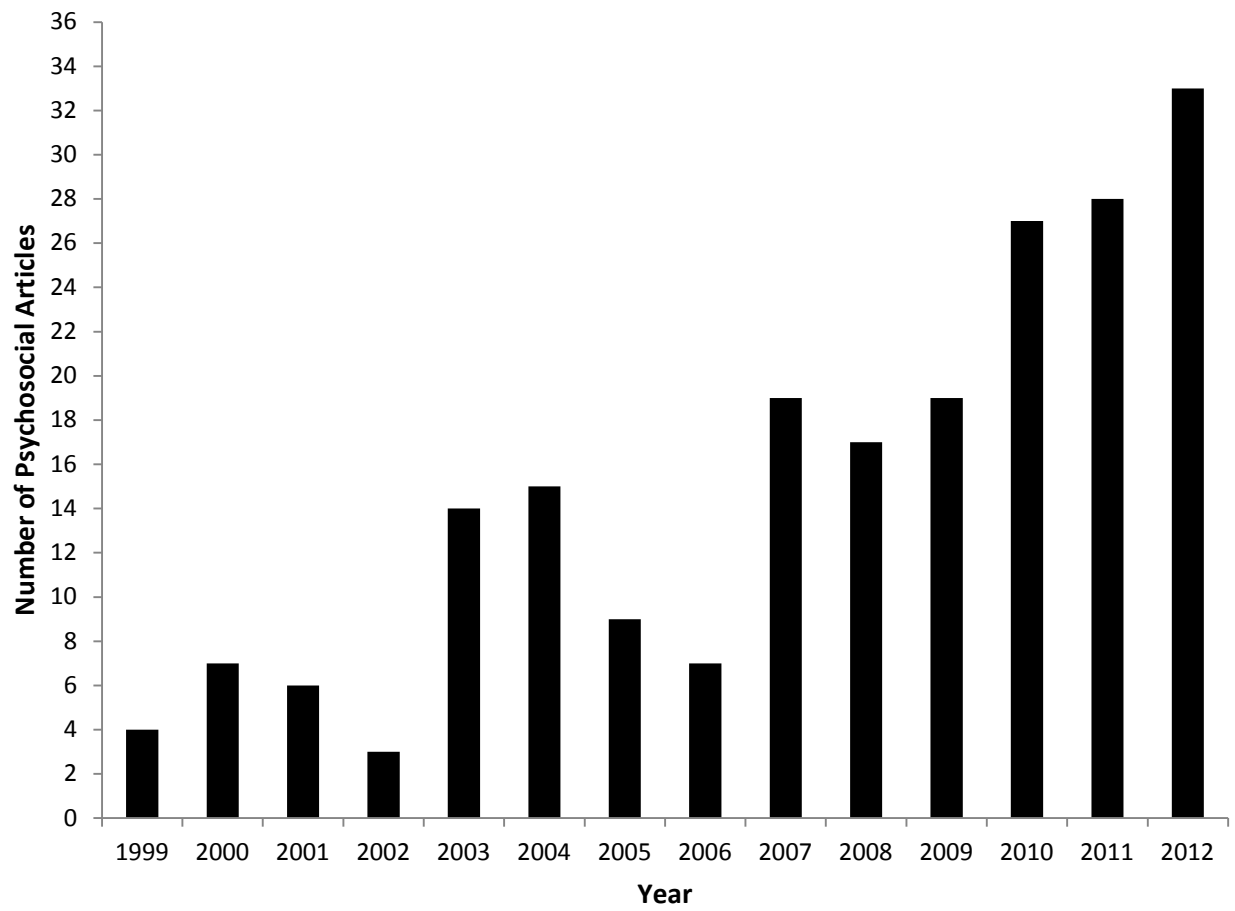


Figure 4. Type of studies and trend over time for Study Type (n = 208)

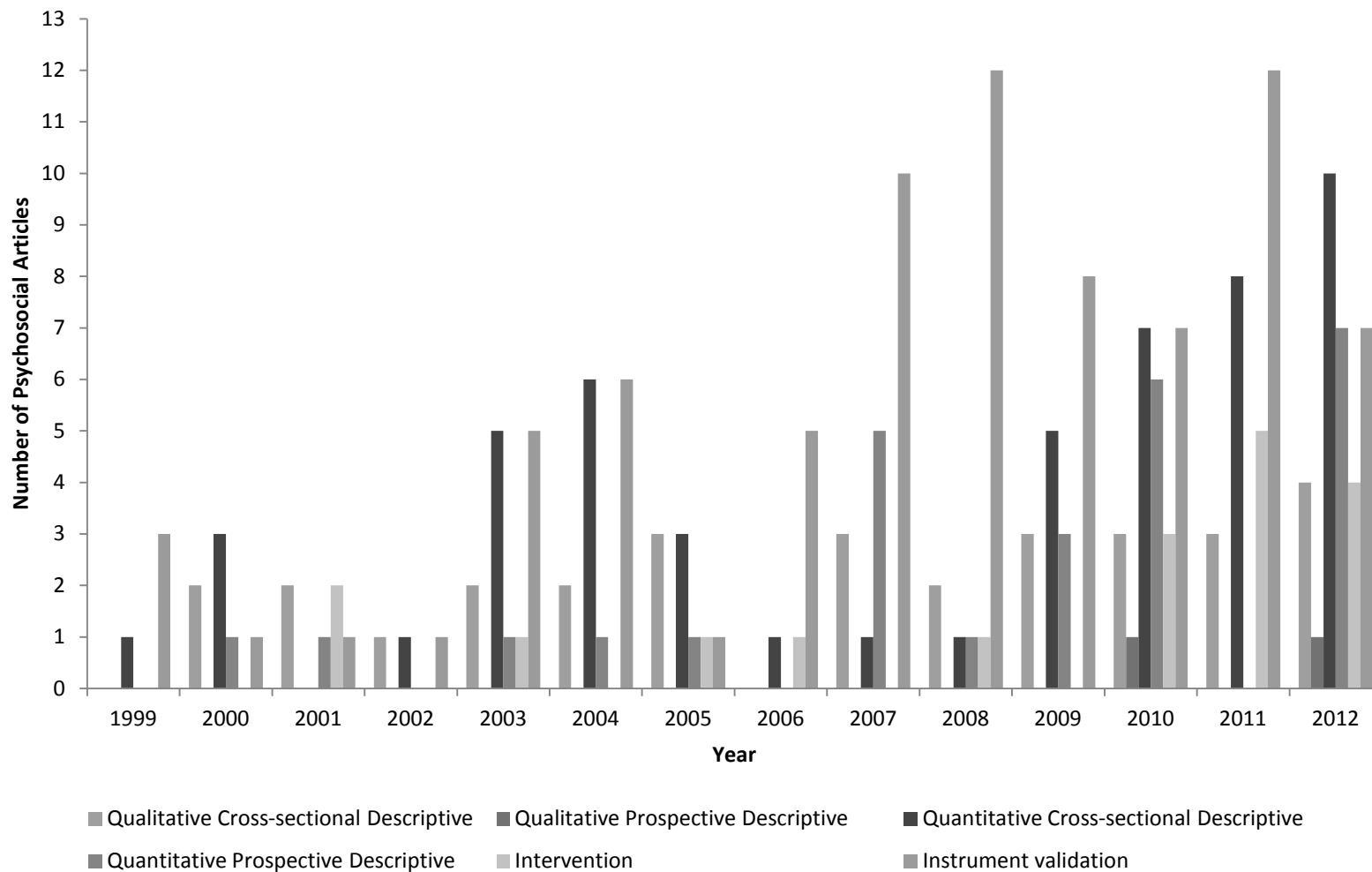
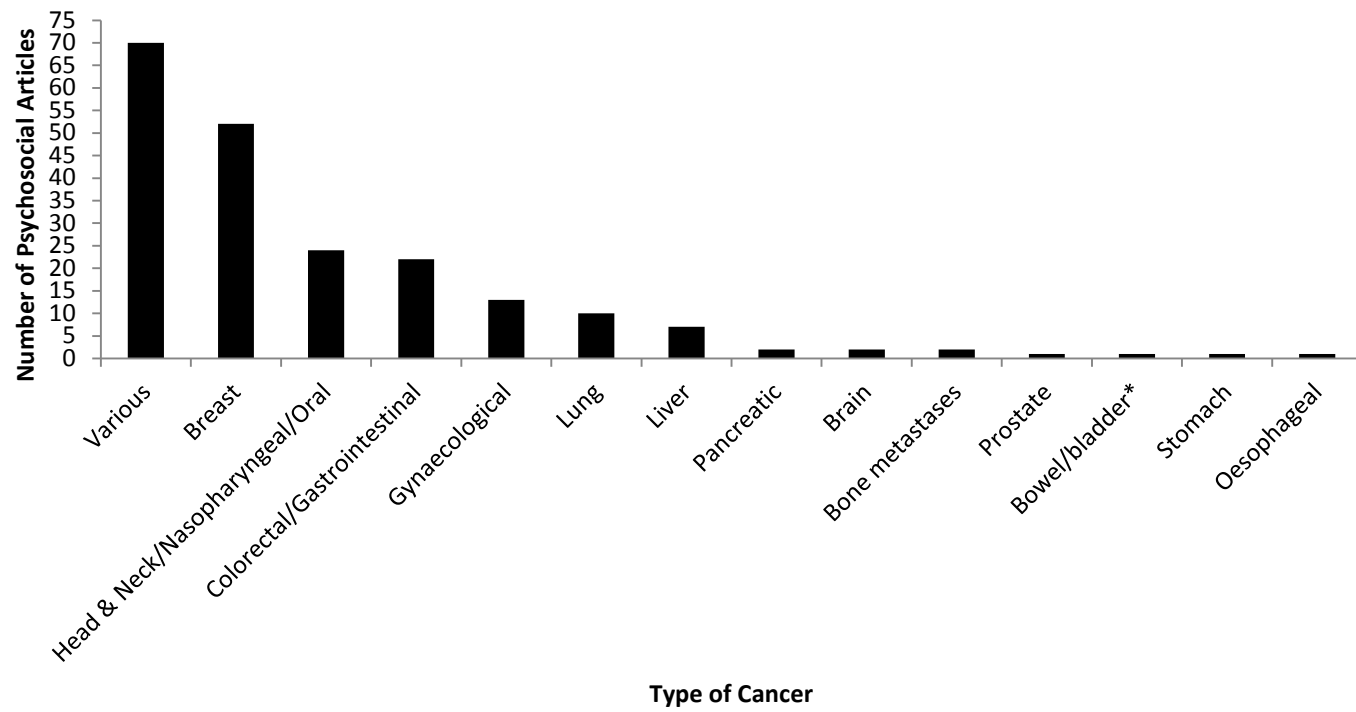


Figure 5. Cancer Type Represented in Psycho-oncology Articles in Chinese regions (n=208)



*Two samples of patients in a single study