GENV332

Litteraturliste våren 2017

Etikk:

Biesecker LG, Burke W, Kohane I, Plon SE, Zimmern R. (2012). Next generation sequencing in the clinic: are we ready? Nat Rev Genet 13: 818-24 **(II)**

Bioteknologirådet (2013). Innspill til regulering av genomundersøkelser i bioteknologiloven. http://www.bioteknologiradet.no/filarkiv/2013/02/Innspill-til-regulering-av-genomundersøkelser-i-bioteknologiloven-HOD-14.02.13.pdf

Bioteknologirådet (2012). Forslag til veileder og retningslinjer for bruk av genomsekvensering og genomdata i klinikk og forskning – fra arbeidsgruppe. http://www.bioteknologiradet.no/filarkiv/2012/11/Veileder_genomsekvensering_091112_til_nett.pdf

Boyle RJ, Savulescu J. (2001). Ethics of using preimplantation genetic diagnosis to select a stem cell donor for an existing person. BMJ; 323:1240-1243. **(II)**

Clayton, E. W. (2010). Currents in Contemporary Ethics. The Journal of Law, Medicine & Ethics, 38: 697–700. **(II)**

Corrigan, O. (2003). Empty ethics: the problem with informed consent. Sociology of Health & Illness, 25: 768–792. **(II)**

Deans Z, Newson AJ. (2011). Should non-invasiveness change informed consent procedures for prenatal diagnosis? Health Care Analysis 19: 122-32 **(II)**

Duncan, R. E., Gillam, L., Savulescu, J., Williamson, R., Rogers, J. G. and Delatycki, M. B. (2008). "You're one of us now": Young people describe their experiences of predictive genetic testing for Huntington disease (HD) and familial adenomatous polyposis (FAP). Am. J. Med. Genet., 148C: 47–55. **(II)**

Evans JP, Berg JS, Olshan AF, Magnuson T, Rimer BK. (2013). We screen newborns, don't we?: realizing the promise of public health genomics. Genet in Med 15: 332-4. **(II)**

Forrest K et al. (2003). To Tell or Not to Tell: Barriers and facilitators in family communication about genetic risk. Clinical Genetics 2003; 64: 317-326. **(II)**

Hallowell N, Foster C, Eeles R, Ardern-Jones A, Murday V, Watson M (2003). Balancing autonomy and responsibility: the ethics of generating and disclosing genetic information. Journal of Medical Ethics 29: 74-79. **(II)**

Helgesson G. (2012). In defence of broad consent. Cambridge Quart of Healthcare Ethics 21: 40-50. **(II)**

Herring J, Foster C. (2012). "Please Don't Tell Me": The Right Not To Know. Cambs Quart of Healthcare Ethics 21: 20-29. **(II)**

Kaye J, Boddington P, de Vries J, Hawkins N Melham K. (2010). Ethical implications of the use of whole genome methods in medical research. EJHG 18: 398-403. **(II)**

Kelly, S. E. (2009). Choosing not to choose: reproductive responses of parents of children with genetic conditions or impairments. Sociology of Health & Illness, 31: 81–97. **(II)**

Michael Parker. (2012). Ethical Problems and Genetics Practice. Cambridge: Cambridge University Press. **(II)**

Pilnick A. (2002). What 'most people' do: exploring the ethical implications of genetic counselling. New Genetics and Society 21: 339-350. **(II)**

Raz AE. (2005). Disability rights, prenatal diagnosis and eugenics: a crosscultural view. J Genet Counseling 14: 183-187. **(II)**

Ruyter, K., Førde, R., Solbakk, J.H. (2014). Medisinsk og helsefaglig etikk. Gyldendal akademisk. **(I)**

Wade, C.H., Wilfond, B.S. (2006): Ethical and Clinical Practice Considerations for Genetic Counselors Related to Direct-to-Consumer. Marketing of Genetic Tests. American Journal of Medical Genetics Part C; 142C: 284-292. **(II)**

Jus:

Molven, O. (2015). Helse og jus. Gyldendal Norsk Forlag, 8. utgave. **(I)**

Lov om biobanker (biobankloven). (2003-02-21 nr12**) (III)**

Lov om helsepersonell m.v. (helsepersonelloven). (2003-08-29-87). **) (III)**

Lov om humanmedisinsk bruk av bioteknologi m.m. (bioteknologiloven). (2004-06-25-45). **) (III)**

Lov om pasientrettigheter (pasientrettighetsloven). (2005-12-21-12). **(III)**

Lov om spesialhelsetjenesten (spesialhelsetjenesteloven) (2005-12-21-127). **) (III)**

Krise / stress / mestring:

Carlsson AH, Bjorvatn C, Engebretsen LF, Berglund G & Natvig GK. (2004). Psychosocial factors associated with quality of life among individuals attending genetic counseling for hereditary cancer. Journal of genetic counselling 425 – 445. **(II)**

Gopie, J.P., Vasen, H.F.A., Tibben, A. (2012). Surveillance for hereditary cancer: Does the benefit outweigh the psychological burden? – A systematic review. Critical Reviews in Oncology Hematology 83 (2012) 329-340. **(II)**

Holloway A & Watson H E (2002). Role of self-efficacy and behaviour change. International Journal of Nursing Practice 8: 106-115. **(II)**

Lazarus, R.S (1993). Coping theory and Research: Past, Present and Future. Psychosomatic Medicine 55; 234-247. **(V)**

Resta R.G (ed.) (2000). Psyche and Helix, psychological aspects of genetic counseling- essays by Seymour Kessler. Wiley-Liss, 1th edition (side 68-73). **(V)**

Kommunikasjon:

Baile, W. F., Buckman, R., Lenzi, R., Glober, G., Beale, E. A., & Kudelka, A. P. (2000). "SPIKES—a six-step protocol for delivering bad news: application to the patient with cancer". The oncologist, 5(4), 302-311. **(II)**

Case, D. O., Andrews, J. E., Johnson, J. D., & Allard, S. L. (2005). "Avoiding versus seeking: the relationship of information seeking to avoidance, blunting, coping, dissonance, and related concepts." Journal of the Medical Library Association, 93(3), 353. **(II)**

CETL (2010). Feedback Opportunities, A Training Resource for Healthcare Professionals 1 Handout: Breaking bad news. **(VI)**

Kringlen, E, Finset, A. (2006). Den kliniske samtalen – kommunikasjon og pasientbehandling. Oslo: Gyldendal akademisk, 2. Utgave (kap. 1, 2, 5, 6, 9). **(I)**

Resta R.G (ed.) (2000). Psyche and Helix, psychological aspects of genetic counseling- essays by Seymour Kessler. Wiley-Liss, 1.utgave. (s. 1-19, 73-99). **(V)**

Rosenzweig, M. Q. (2012). Breaking bad news: a guide for effective and empathetic communication." The Nurse Practitioner, 37(2), 1-4**. (V)**

Vos, J., Jansen, A.M., Menko, F., Van Asperen, C.J., Stiggelbout, A.M., Tibben, A. (2011). Family communication matters: The impact of telling relatives about unclassified variants and uninformative DNA-test results. Genetics in medicine (2011) 13, 333-341. **(II)**

Livskvalitet:

Burckhardt, C. S., & Anderson, K. L. (2003). The Quality of Life Scale (QOLS): reliability, validity, and utilization. Health and quality of life outcomes, 1(1), 60. **(II)**

Ericsson M, Lindstrøm B (2008). A salutogenic interpretation of the Ottawa Charter. Health Promotion International, Vol 3 n0 2, 190- 199. **(II)**

Ferrans et al (2005). Conceptual Model of Health Related Quality of Life. Journal of Nursing Scholarship, 37:4, 336-342. **(II)**

Kaplan RM (2002). Quality of life and chronic illness. I Christensen AJ & Antoni MH (red) Chronic physical disorders. Side 1 – 24. **(III)**

Mallinson S (2002). Listening to respondents: a qualitative assessment of Short-Form 36 Health Status Qustionnaire. Social Science & Medicine, 54: 11 – 21. **(II)**

Moons P, Budts W & De Geest S (2006). Critique of the conceptualisation of quality of life: A review and evaluation of different conceptual approaches. International journal of nursing studies. 891 – 901. **(II)**

Næss S (2001). Livskvalitet som psykisk velvære. Tidsskrift Nor Lægeforen, side 1940 – 4**. (V)**

Vallerand AH, Payne JK (2003). Theories and conceptual models to guide quality of life research. I King CR & Hinds P. (red.) 2003: Quality of life. From nursing and patient perspectives, side 45 – 64 **(V)**

Genetisk veiledning:

Andersen, J., Öyen, N., Bjorvatn, C., Gjengedal, E. (2008): Living with Long QT syndrome: A qualitative study of coping with increased risk of sudden cardiac death. Journal of Genetic Counseling, 17, 489-498. **(II)**

Bjorvatn, C., Eide, G., Hanestad, B., Havik, O (2008). Anxiety and depression among subjects attending genetic counselling for hereditary cancer, 71, 234-243 **(II).**

Brunstad, A., Tegnander B. (2010). Jordmorboka - ansvar, funksjon og arbeidsområde" Akribe (30-40, 170-184, 192) **(III)**

Carlsson, A.H., Bjorvatn, C., Engebretsen L.F., Berglund, G. & Natvig, G.K (2004). Psychosocial factors associated with quality of life among individuals attending genetic counselling for hereditary cancer. Journal of Genetic Counselling, 425 – 445. **(II)**

Clarke, A. (2014). Harper's Practical Genetic Counselling. Edward Arnold (Publishers) Ltd. 8. Edition.

Hamang, A., Eide, G., Nordin, K., Rokne, B., Bjorvatn, C., Öyen, N. (2010). Health status in patients at risk of inherited arrythmias and sudden unexpected death compared to the general population. BMC, 11, 1-10. **(II)**

Kwong, A.,Chu, A.T.W. (2012). What made her give up her breasts: a Qualitativ Study on Decisional Considerations for Contralateral prophylactic Mastectomy among Breast Cancer Survivors Undergoing BRCA1/2 Genetic testing. Asian Pacific Journal of Cancer Prevention, Vol 13, 2012. **(V)**

Nordin, K.,Lidén, A., Hansson, M., Rosenquist, R., Berglund, G (2002). Coping style, psychological distress, risk perception, and satisfaction in subjects attending genetic counselling for hereditary cancer. Journal of medical genetics, 39, 689-694. **(II)**

Paus B. (2009). Klinisk genetikk – en innføringsbok. Gyldendal norsk forlag AS., 1. utg **(I)**

Resta R.G (ed.) (2000). Psyche and Helix, psychological aspects of genetic counseling - essays by Seymour Kessler. John Wiley and Son Ltd, 1th edition. (s. 35-63, 99-173). **(V)**

Schneider K. (2012). Counseling about cancer; strategies for genetic counseling. Wiley-Blackwell, 3. utgave.(side 309-444). **(I)**

I: Anbefalt å kjøpe.

II: Hentes i databasene i bibliotekportalen (de fleste i PubMed)

III: Tilgjengelig som e-bok (UBB)

IV: Hentes på www.lovdata.no

V: Blir utlevert