Patient Education and Counseling 103 (2020) 1657–1661

Contents lists available at ScienceDirect

Patient Education and Counseling

journal homepage: www.elsevier.com/locate/pateducou

Discussion

Counselling for prenatal anomaly screening—A plea for integration of existential life questions

Christina Prinds[a,b,*], Janneke Gitsels-van der Wal[a], Neeltje Crombag[d], Linda Martin[c]

[a] University of Southern Denmark, Institute of Clinical Research, Odense C, Denmark
[b] University College South Denmark, Haderslev, Denmark
[c] Amsterdam UMC, Vrije Universiteit Amsterdam, Midwifery Science, AVAG, Amsterdam Public Health Research Institute, De Boelelaan 1117, Amsterdam, The Netherlands
[d] University of Leuven, Department of Development and Regeneration, Biomedical Sciences, Belgium

ARTICLE INFO

Article history:
Received 5 November 2019
Received in revised form 4 March 2020
Accepted 27 March 2020

Keywords:
Existential
Life questions
Prenatal
Screening
Counsellor
Decision-making

ABSTRACT

The availability in many countries of new prenatal anomaly screening methods, such as the non-invasive prenatal test (NIPT), and the potential broadening of testing for genetic conditions, creates an ongoing debate about the accompanying existential dilemmas at both societal level and for individual new parents. In many countries, the main goal of counselling for prenatal anomaly screening is to facilitate the reproductive decision-making process of future parents. Therefore, counsellors share information to enable a woman and her partner to think about the pros and cons of participating in screening, try to clarify possible moral dilemmas, and dwell on existential life questions. In line with the CanMEDS framework, healthcare professionals must combine the role of communicator (providing *health education*) with that of professional (by recognising and responding to existential life questions while facilitating *decision-making*). This is not easy but it is essential for providing balanced counselling. At present, counselling tends to be sufficient regarding *health education*, whereas *guidance in decision-making*, including attention for existential life questions and philosophy of life, offers room for improvement. In this paper, we suggest slowing down and turning the traditional prenatal counselling encounter upside down by starting as a counselling professional instead of a healthcare information sharing communicator and thus making the story of the woman and her partner, within their societal context, the starting point and the basis of the counselling encounter.

1. Existential life questions in maternity care settings

During the last decades, pregnant women in Europe and North America have been enrolled in continuously developing prenatal anomaly screening (PNS) programmes. Such programmes generally comprise first-trimester screening for aneuploidies such as Down, Edwards' and Patau syndromes, and second-trimester screening for structural foetal anomalies such as neural tube and heart defects. Non-invasive prenatal testing (NIPT) has broadened the scope of screening, and it is expected to expand further within the next few years. Debate surrounding the dilemmas arising from routine screening, for both society as a whole as well as for individual new parents, is ongoing, complex and highly relevant [1–10].

From a societal perspective, dilemmas include, for example, the scope of the test offer and securing the medical ethical principle of patient autonomy. As for the test offer, there are no straightforward answers to questions about eligibility, quality of tests and the choice of target anomalies, or the ethical dilemmas around gender information. Regarding patient autonomy, as prenatal screening becomes increasingly regarded as part of routine care, it could become extremely difficult to guarantee both freedom of choice and informed decision-making. Consequently, individual dilemmas might arise, such as how to respond in situations in which a routine test offer leads to questions about terminating the pregnancy, particularly where individuals, based on their world-views, want to protect the life of their unborn child from the day of conception onward. Furthermore, routinization might lead to less

* Corresponding author at: University of Southern Denmark, Institute of Clinical Research, Research Unit of Gynaecology and Obstetrics (50%), Kløvervænget 10, 5000 Odense C., Denmark.
E-mail address: cprinds@health.sdu.dk (C. Prinds).

https://doi.org/10.1016/j.pec.2020.03.025
0738-3991/

informed decision-making and thus to moral dilemmas in case of unfortunate outcomes of screening that are not expected by the parents [11].

Many uncertainties still surround decision-making in prenatal screening: the potential findings of prenatal anomaly screening comprise a broad variety of genetic disorders with very diverse and sometimes unknown clinical consequences [12–15]. Therefore, it is important to provide *health education* regarding the aim of prenatal anomaly screening and its possibilities through medical expertise. In countries offering prenatal anomaly screening, medical counsellors are easily interpreted as exponents of (medical) society, usually focusing primarily on the advantage of screening to detect an anomaly to manage or monitor pregnancy outcomes [11,16–19]. However, parents might have other motivations for both attending counselling and/or entering prenatal screening programmes [20]. Motivations for parents could be confirming the health of the unborn child or to be able to comprehend the life situation of expecting a child [21–24]. These conflicting motivations must be recognised in order to provide patient-centred counselling.

Pregnancy and childbirth has been described as a liminal state in life, referring to anthropologist Van Gennep's descriptions of rites of passage [25]. Building on his work, the American anthropologist Davis-Floyd explains pregnancy as the state where a woman is "in-between", neither being a normal member of society, nor a mother, raising many ethical and existential life questions [26]. We understand existential life questions in a European existential philosophical tradition valuing an active questioning of life conditions, dilemmas or life changes, allowing people to live authentic lives [27,28]. In relation to parenthood and PNS, vulnerability, responsibility, and values in life are often present, reflected in stories about how to be a 'good enough' mother or father: Can you love your child no matter what child you have? If you are expecting your third child, how can you have enough 'room' in your heart for one more? What if something is wrong with your child; how is love affected then? How can you protect your child from any harm (and is it harmful being born if you are a sick child)? How will your relationship with your partner/own parents be affected by this (potentially sick or disabled) child to come? How will you change as a human; will you make other choices in your life? However, such questions are seldom explicitly discussed in maternity care settings or during counselling for prenatal anomaly screening [29–33]. This paper argues that consideration of parents' existential life questions should underpin all counselling for prenatal anomaly screening.

2. Counselling tends to lag behind

In this paper 'counsellors' are understood as primarily grounded in health care and medical expertise, mostly with a strong focus on the role as communicator, who establish professional therapeutic relationships with patients and their families and share healthcare information with them [41]. Backgrounds of counsellors in this paper include, for example, midwives, obstetricians, nurses, sonographers and GPs, but might vary between countries. Other forms of counselling related to prenatal anomaly screening from, for example, complementary medicine, religious guidance or psychotherapy, are not included.

Three aspects are important in prenatal counselling: *a relationship of trust between the counsellor and patient; health education;* and *decision-making support* [34]. Recent studies have shown that the first two of these aspects are generally considered sufficient, although *health education* during counselling for prenatal anomaly screening tends to lag behind the rapid medical developments in the field of prenatal aneuploidy [35]. However, the aspect of *decision-making support*, including attention for existential life questions and philosophy of life, requires improvement [33,36–38]. Many factors contribute to the instrumental focus on *health education* in prenatal counselling: contextual factors (e.g. political, organisational); professional factors (e.g. attitudes and education); and parental factors (e.g. language proficiency, health literacy, expectations). Addressing these multiple factors might be experienced by counsellors as time-consuming and lead to lack of deeper conversations about values and beliefs, which then might cause discomfort in starting these conversations, because it feels outside the scope of expertise [39]. Learning to relate to values or beliefs in counselling is challenging and, for most health care providers, beyond their expertise. Since the urgency to increase such competencies seems large, other fields of health care, for example in palliative care, have initiated new educational initiatives focusing on skills to discuss spiritual aspects of life within a health care setting [40]. A similar initiative is required to develop counselling skills related to prenatal screening.

In the Netherlands, a widely recognized need to optimize the quality of counselling for prenatal anomaly screening has thus emerged [20,35]. The Dutch government has set new goals: from 2017 onwards, Dutch counsellors in prenatal screening are obliged, among other things, to retrain their counselling skills, especially in decision-making support, every two years [35]. Therefore, counselling as a concept will be elucidated in the forthcoming section.

3. Counselling in a non-instrumental perspective

The American psychologist Carl Rogers – one of the founders of a client-centered approach in psychotherapy – states that a basic principle of counselling is *non-directiveness:* accepting emotions, values, and decisions of the patient both rationally and emotionally, and thus being sensitive towards them [42,43]. Accepting is different from adopting these views, emotions, and decisions or agreeing with them. *Non-directive* counselling consists of three aspects. First, it means having an *unconditional, positive perception* of the patient and her choices, even if they are not agreeable to the counsellor [3,44]. Second, within non-directive counselling, *authenticity* is important. This can be achieved, for example, through self-reflection of the counsellor regarding how one's own existential life questions are valued and how they might influence encounters with patients [27,45]. Lastly, *empathy* is an essential aspect of a non-directive attitude. Empathy has different levels, but the starting point of all empathy is the acknowledgement that life questions are influenced by all life-dimensions; for example, the physical, psychological, social, and spiritual dimensions [46,47]. Therefore, both in PNS counselling and in cases of a positive screening followed by a diagnosed congenital anomaly, where parents face essential decisions (continuation or termination of pregnancy) we believe that it is essential to explore the values of a woman and her partner, and their reflections on existential life questions, in order to facilitate decisions [13,48].

4. Being a medical expert demands combining roles

The aim of counselling for prenatal anomaly screening is to offer future parents the possibility of making an informed choice about whether to obtain information regarding the health of their foetus, which may open the need to make further decisions [13]. Consequently, PNS counselling involves two distinct roles which are both part of the CanMEDS framework: on one hand, the *communicator* who shares *health* information and builds *a relationship of trust;* and on the other hand, the *professional,* recognizing, introducing and addressing ethical dilemmas during the provision of *decision-making support* [34,41,49]. Counselling as

defined above may not be a distinctive part of existing CanMEDS frameworks of medical experts but, according to the role-description of being communicator and professional, being a medical expert implies also to recognize and respond to ethical issues [50]. To do so, we believe, requires the capability to be non-directive in a Rogers-inspired way [42,43].

As visualised in Fig. 1, PNS counselling is founded on strong *health education skills*, which most counsellors already have [41]. To create a *relationship of trust*, being *non-directive* is vital. Through these two basic aspects (layers), it becomes realistic to fulfil the aim of *counselling* in also providing *decision-making support*.

In theory, the counsellor is the expert of prenatal anomaly screening, and the patient is the expert regarding her philosophy of life and values regarding (unborn) life. Counselling is essentially patient-oriented and patient-specific. If a counsellor is aligned with herself (e.g. congruent in thinking, talking and acting), mindfully present, and attuned to the patient, the counsellor can determine what role suits best for this patient at a given time: a communicator or a professional, or a specific combination of both [45,51,52]. In practice it is more complicated: being a communicator positions the counsellor in a medical regime, where paradigms of health lean onto medical scientific knowledge, often not emphasising personal values or existential life questions [26,53,54]. Furthermore, the communicator role may compromise the basic principle of being a counsellor where an equal patient-counsellor relationship is the aim, based on mutual trust and respect, in which individual competencies, roles, and interdependence of the interlocutors are acknowledged [20,55]. Combining the role of being a professional (e.g. by providing *decision-making support including existential life questions*) with the role of communicator (e.g. by providing *health education*) is not easy, but it is essential [56,57].

5. Recommendations for counselling practice

Traditionally, counselling for prenatal anomaly screening tends to start with the medical-counsellor sharing information in his role as a communicator, eventually followed by explicitly addressing ethical dilemmas and facilitating the decision-making process of the woman and her partner from the role as a professional. When it comes to prenatal anomaly screening, we suggest slowing down and turning this traditional prenatal counselling encounter upside down.

To start with counselling rather than sharing information requires making the starting point and the basis of the counselling the perspective of the prospective parents instead of the available test-information. Therefore, active patient involvement is essential. This is highlighted also in the model of shared decision making (SDM) suggested by Elwyn et al. (2012), consisting of three key steps: choice talk, option talk and decision talk. In line with our recommendations, this model also suggests putting the perspective of the patient central during the start of the decision-making process, which is fundamental for patient-centered communication (SDM, choice talk) [55]. In line with the model of SDM, the counsellor should first explore to what extent expecting parents want information about possible congenital anomalies in her/their foetus and for what purpose [33,36]. Different life experiences and existential life questions may be underlying reflections in this phase. If necessary, the counsellor can shift to sharing additional information that complements the existing knowledge of the woman and partner in order to minimize information-asymmetry (SDM, option talk) [55]. Next, the counsellor again shifts to counselling, by exploring how the woman and partner perceive and appreciate the consequences of the content discussed in the light of her/their existential life values and how she/they feel life should be lived (SDM, decision talk) [55]. The woman might face a moral dilemma where she struggles with the existential theme of 'fate versus free will' and the two competing choices. Dilemma counselling can facilitate the parents' acceptance of the reality of these competing choices, enabling them to explore their existential life values and eventually create a decisional balance in which the pros and cons of participation in prenatal screening from the woman's perspective are equally listed, both verbally and non-verbally. In the end, counselling can be completed by asking the woman to describe her attitudes towards prenatal anomaly screening and what it means to her given the present question of whether or not to take this screening. This decision can, but does not necessarily have to, be taken during the counselling (SDM, decision talk) [55]. The main goal of the counselling is to make the woman and her partner think about the pros and cons of participating in anomaly screening, to clarify possible moral dilemmas, and dwell on existential questions so that she feels empowered to make an informed choice with dignity and existentially healthy lives in mind [36,58]. Moreover, in our recommendations we suggest letting existential life questions stand as a background colour impacting all phases of the counselling process and not merely stand as a single question related to a specific phase.

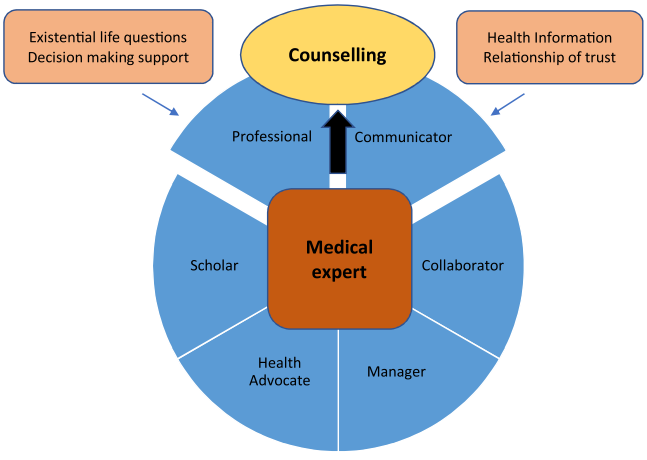

Fig. 1. Counselling including existential life questions included in CanMED inspired model.

6. Recommendations for counselling education

To combine the role of communicator with the role of professional in order to be a medical expert and counsellor is a comprehensive task, which will take a long time. To accomplish such merge requires, first and foremost, political and institutional acknowledgement and belief that the counselling role is part of being a medical expert, and thus accepting how existential life questions might arise during pregnancy and PNS. Arising from that starting point come initiatives to start educating counsellors at both BA- MA and postgraduate level concerning existential aspects of life [40]. To do so requires role models; thus a further recommendation is to present a choice for HCP's to focus on *counsellor education*, rather than expecting all HCP's to act as counsellors.

7. Leadership to make it happen

To create a working space in which high-quality medical counselling can take place, we encourage policymakers, interest organisations and leaders of health counsellors and health education to strongly promote that counselling for prenatal anomaly screening should include not only the provision of

information but also a conversation about existential life questions and values of life rooted in all dimensions of humanity. In this encouragement, we acknowledge the difficulties embedded in the settings where maternity services do not include screening yet but in which pregnancy nevertheless prompts women and their partners also to consider existential questions of life. To address these is a complex and long-term task imposing political and structural will towards more non-directive PNS counselling for all women.

Role of funding

None of the authors have financial or other conflicts of interests related to the subject of this study. Moreover, we were funded solely by our universities and university colleges.

Declaration of Competing Interest

The authors declare that they have no conflict of interest.

References

[1] A. Møller, I. Vogel, O.B. Petersen, S. Lou, Danish sonographers' experiences of the introduction of "moderate risk" in prenatal screening for Down syndrome, J. Pregnancy 2018 (2018) 1–7.
[2] I.C.B. Lund, N. Becher, O.B. Petersen, M. Hill, L. Chitty, I. Vogel, Preferences for prenatal testing among pregnant women, partners and health professionals, Danish Med. J. 65 (5) (2018).
[3] L. Martin, J.T. Gitsels-van der Wal, M.T. Pereboom, E.R. Spelten, E.K. Hutton, S. van Dulmen, Midwives' perceptions of communication during videotaped counseling for prenatal anomaly tests: how do they relate to clients' perceptions and independent observations? Patient Educ. Couns. 98 (5) (2015) 588–597.
[4] B. Griffin, S. Edwards, L.S. Chitty, C. Lewis, Clinical, social and ethical issues associated with non-invasive prenatal testing for aneuploidy, J. Psychosom. Obstet. Gynaecol. 39 (1) (2018) 11–18.
[5] K.O. Kagan, M. Hoopmann, R. Hammer, R. Stressig, P. Kozlowski, Screening for chromosomal abnormalities by first trimester combined screening and noninvasive prenatal testing, Ultraschall Med. 36 (1) (2015) 40–46.
[6] A. Sachs, L. Blanchard, A. Buchanan, E. Norwitz, D.W. Bianchi, Recommended pre-test counseling points for noninvasive prenatal testing using cell-free DNA: a 2015 perspective, Prenat. Diagn. 35 (10) (2015) 968–971.
[7] Sundhedsstyrelsen, Retningslinjer for fosterdiagnostik - prænatal information, risikovurdering, rådgivning og diagnostik [guidelines for prenatal diagnostics - prenatal information, risk assessment, counselling and diagnostics], Danish Health Authority (Sundhedsstyrelsen), (2017) Copenhagen.
[8] D. Oepkes, G.C. Page-Christiaens, C.J. Bax, M.N. Bekker, C.M. Bilardo, E.M. Boon, G.H. Schuring-Blom, A.B. Coumans, B.H. Faas, R.H. Galjaard, A.T. Go, L. Henneman, M.V. Macville, E. Pajkrt, R.F. Suijkerbuijk, K. Huijsdens-van Amsterdam, D. Van Opstal, E.J. Verweij, M.M. Weiss, E.A. Sistermans, Trial by Dutch laboratories for evaluation of non-invasive prenatal testing. Part I-clinical impact, Prenat. Diagn. 36 (12) (2016) 1083–1090.
[9] M. Neyt, F. Hulstaert, W. Gyselaers, Introducing the non-invasive prenatal test for trisomy 21 in Belgium: a cost-consequences analysis, BMJ Open 4 (11) (2014)e005922.
[10] S.L. Warsof, S. Larion, A.Z. Abuhamad, Overview of the impact of noninvasive prenatal testing on diagnostic procedures, Prenat. Diagn. 35 (10) (2015) 972–979.
[11] M. Best, The dilemma of prenatal screening, Ethics Med. Int. J. Bioethics 34 (2) (2018) 113–167.
[12] S. Ahmed, H. Yi, D. Dong, J. Zhu, H. Jafri, Y. Rashid, O.M. Ngan, M. Ahmed, Interpretations of autonomous decision-making in antenatal genetic screening among women in China, Hong Kong and Pakistan, Eur. J. Hum. Genet. 26 (4) (2018) 495–504.
[13] J.T. Gitsels-van der Wal, L. Martin, J. Mannien, P. Verhoeven, E.K. Hutton, H.S. Reinders, Antenatal counselling for congenital anomaly tests: pregnant muslim Moroccan women's preferences, Midwifery 31 (3) (2015) e50–7.
[14] D.W. Bianchi, Should we 'open the kimono' to release the results of rare autosomal aneuploidies following noninvasive prenatal whole genome sequencing?: NIPT and rare autosomal aneuploidies, Prenat. Diagn. 37 (2) (2017) 123–125.
[15] A. Cernat, C. De Freitas, U. Majid, F. Trivedi, C. Higgins, M. Vanstone, Facilitating informed choice about non-invasive prenatal testing (NIPT): a systematic review and qualitative meta-synthesis of women's experiences, BMC Pregnancy Childbirth 19 (1) (2019) 27.
[16] C. Ferrier, F. Dhombres, L. Guilbaud, I. Durand-Zaleski, J.M. Jouannic, Ultrasound screening for birth defects: a medico-economic review, Gynecol. Obstet. Fertil. Senol. 45 (7–8) (2017) 408–415.
[17] A. de Jong, G.M. de Wert, Prenatal screening: an ethical agenda for the near future, Bioethics 29 (1) (2015) 46–55.
[18] M. Van Zwieten, Het belang van een weloverwogen keuze - maar wat behelst de keuze? De complexe besluitvorming bij prenataal onderzoek, De Psychol. 43 (2008) 20–25.
[19] G. Wu, R. Li, C. Tong, M. He, Z. Qi, H. Chen, T. Deng, H. Liu, H. Qi, Non-invasive prenatal testing reveals copy number variations related to pregnancy complications, Mol. Cytogenet. 12 (1) (2019) 38.
[20] L. Martin, E.K. Hutton, E.R. Spelten, J.T. Gitsels-van der Wal, S. van Dulmen, Midwives' views on appropriate antenatal counselling for congenital anomaly tests: do they match clients' preferences? Midwifery 30 (6) (2014) 600–609.
[21] E. Sahlin, M. Nordenskjold, P. Gustavsson, J. Wincent, S. Georgsson, E. Iwarsson, Positive attitudes towards non-invasive prenatal testing (NIPT) in a Swedish cohort of 1,003 pregnant women, PLoS One 11 (5) (2016)e0156088.
[22] T. Carlsson, B. Balbas, E. Mattsson, Written narratives from immigrants following a prenatal diagnosis: qualitative exploratory study, BMC Pregnancy Childbirth 19 (1) (2019) 154.
[23] J. Roberts, F.E. Griffiths, A. Verran, C. Ayre, Why do women seek ultrasound scans from commercial providers during pregnancy? Sociol Health Illness 37 (4) (2015) 594–609.
[24] M. van den Berg, D.R. Timmermans, D.L. Knol, J.T. van Eijk, D.J. de Smit, J.M. van Vugt, G. van der Wal, Understanding pregnant women's decision making concerning prenatal screening, Health Psychol. 27 (4) (2008) 430–437.
[25] V.A. Gennep, The Rites of Passage, University of Chicago Press, Chicago, 1966.
[26] R. Davis-Floyd, Birth as an American Rite of Passage, University of California Press, Berkely and Los Angeles, California, 2003.
[27] B. Jacobsen, Invitation to Existential Psychology. A Psychology for the Unique Human Being and Its Applications in Therapy, John Wiley & Sons Ltd, Chichester, 2007.
[28] E. van Deurzen, Existential therapy, Dryden's Handbook of Individual Therapy, SAGE, London, 2007.
[29] C. Prinds, D. Hvidtjorn, O. Mogensen, A. Skytthe, N.C. Hvidt, Existential meaning among first-time full-term and preterm mothers: a questionnaire study, J. Perinat. Neonatal Nurs. 28 (4) (2014) 271–279.
[30] C. Prinds, N.C. Hvidt, O. Mogensen, N. Buus, Making existential meaning in transition to motherhood - a scoping review, Midwifery 30 (6) (2014) 733–741.
[31] J. Wojtkowiak, S. Crowther, An existential and spiritual discussion about childbirth: contrasting spirituality at the beginning and end of life, Spirit. Clin. Pract. 5 (4) (2018) 261–272.
[32] J.T. Gitsels-van der Wal, J. Mannien, L.A. Gitsels, H.S. Reinders, P.S. Verhoeven, M.M. Ghaly, T. Klomp, E.K. Hutton, Prenatal screening for congenital anomalies: exploring midwives' perceptions of counseling clients with religious backgrounds, BMC Pregnancy Childbirth 14 (2014) 237.
[33] J.T. Gitsels-van der Wal, L. Martin, J. Mannien, P. Verhoeven, E.K. Hutton, H.S. Reinders, A qualitative study on how muslim women of Moroccan descent approach antenatal anomaly screening, Midwifery 31 (3) (2015) e43–9.
[34] L. Martin, A.Mv. Dulmen, E. Spelten, Ad. Jonge, Pd. Cock, E. Hutton, Prenatal counseling for congenital anomaly tests: parental preferences and perceptions of midwife performance, Prenat. Diagn. 33 (4) (2013) 341–353.
[35] L. Martin, J.T. Gitsels-van der Wal, M.A. de Boer, M. Vanstone, L. Henneman, Introduction of non-invasive prenatal testing as a first-tier aneuploidy screening test: a survey among Dutch midwives about their role as counsellors, Midwifery 56 (2018) 1–8.
[36] L. Martin, E.K. Hutton, J.T. Gitsels-van der Wal, E.R. Spelten, F. Kuiper, M.T. Pereboom, S. van Dulmen, Antenatal counselling for congenital anomaly tests: an exploratory video-observational study about client-midwife communication, Midwifery 31 (1) (2015) 37–46.
[37] J. Mozersky, V. Ravitsky, R. Rapp, M. Michie, S. Chandrasekharan, M. Allyse, Toward an ethically sensitive implementation of noninvasive prenatal screening in the global context, Hastings Cent. Rep. 47 (2) (2017) 41–49.
[38] J. Mozersky, M.T. Mennuti, Cell-free fetal DNA testing: who is driving implementation? Genet. Med. 15 (6) (2013) 433–434.
[39] T.L. Jones, P. Hamilton, N. Murry, Unfinished nursing care, missed care, and implicitly rationed care: state of the science review, Int. J. Nurs. Stud. 52 (6) (2015) 1121–1137.
[40] M. Best, C. Leget, A. Goodhead, P. Paal, An EAPC white paper on multi-disciplinary education for spiritual care in palliative care, BMC Palliative Care 19 (1) (2020) 9.
[41] J. Frank, L. Snell, S. J (Eds.), CanMEDS 2015 Physician Competency Framework, Royal College of Physicians and Surgeons of Canada, Ottawa, 2015.
[42] D.M. Bartels, B.S. LeRoy, P. McCarthy, A.L. Caplan, Nondirectiveness in genetic counseling: a survey of practitioners, Am. J. Med. Genet. 72 (2) (1997) 172–179.
[43] C.R. Rogers, Counseling and Psychotherapy: Newer Concepts in Practice, Houghton Mifflin, Boston, 1942.
[44] M. Vanstone, E.A. Kinsella, J. Nisker, Information-sharing to promote informed choice in prenatal screening in the spirit of the SOGC clinical practice guideline: a proposal for an alternative model, J. Obstet. Gynaecol. Can. 34 (3) (2012) 269–275.
[45] C.G. Jung, Memories, Dreams, Reflections, paperback ed., Penguin Random House, New York, 1989.
[46] M. Leijssen, Empathy as intrument for effective healthcare [empathie als instrument voor effectieve geneeskunde], in: M. Leijssen, N. Stinckens (Eds.), Wijsheid in Gesprekstherapie, Universitaire Pers Leuven, Leuven, 2004, pp. 313–332.
[47] C. Prinds, Motherhood Transition Through an Existential Lens - Meaning-Making Among Danish First-Time Mothers, Institute of Public Health, University of Southern Denmark Odense, 2014 p. 83.

[48] E. García, D.R.M. Timmermans, E. van Leeuwen, Women's views on the moral status of nature in the context of prenatal screening decisions, J. Med. Ethics 37 (8) (2011) 461–465.
[49] B. Meiser, J. Irle, E. Lobb, K. Barlow-Stewart, Assessment of the content and process of genetic counseling: a critical review of empirical studies, J. Genet. Counsel. 17 (5) (2008) 434–451.
[50] F.L, L. Snell, M. Pauls, R. Kearney, A. Warren, R. Sternszus, R. Cruess, S. Cruess, R. Hatala, M. Dupre', M. Bukowskyj, S. Edwards, J. Cohen, A. Chakravarti, L. Nickell, J. Wright, Professional, in: S.L, J.R. Frank, J. Sherbino (Eds.), CanMEDS 2015 Physician Competency Framework, Royal College of Physicians and Surgeons of Canada, Ottawa, 2015.
[51] K. Klaver, A. Baart, Attentiveness in care: towards a theoretical framework, Nurs. Ethics 18 (5) (2011) 686–693.
[52] P. Kalanithi, When Breath Becomes Air, Vintage Puplishing, New York, 2017.
[53] O. Sigurdson, Existential health. Philosophical and historical perspectives, Tidskrift för litteratur, idéhistoria och religion 6 (2016) 17.
[54] A.R. Dyer, The need for a new "New medical model": a bio-psychosocial-spiritual model, South. Med. J. (2011).
[55] G. Elwyn, D. Frosch, R. Thomson, N. Joseph-Williams, A. Lloyd, P. Kinnersley, E. Cording, D. Tomson, C. Dodd, S. Rollnick, A. Edwards, M. Barry, Shared decision making: a model for clinical practice, J. Gen. Intern. Med. 27 (10) (2012) 1361–1367.
[56] I.C.o.M. (ICM), Philosophy and Model of Midwifery Care, International Confederation of Midwives, Netherlands, 2014.
[57] I.C.o.N. (ICN), in: I.C.o.N. (ICN) (Ed.), ICN Code of Ethics for Nurses, International Council of Nurses (ICN), Geneva, Switzerland, 2012 p. 11.
[58] M.C.B. van Zwieten, The Target of Testing. Dealing With "unexpected" Findings in Prenatal Diagnosis, Amsterdam Public Health, General Practice/Family Medicine, University of Amsterdam, Amsterdam, 2006.