

Storytelling to Enrich the Democratic Debate: The Dutch Discussion on Embryo Selection for Hereditary Breast Cancer

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Abstract

In the Netherlands, the opposition between advocates of embryo selection (preimplantation genetic diagnosis, PGD) and opponents seeking to ban PGD altogether escalated in May and June 2008, shortly after the State Secretary of Health proposed to rescind the ban on PGD for hereditary breast cancer. The clash between the Social Democratic Labour Party and the Reformed Christian Party, both represented in the Dutch Parliament, was ultimately settled in a quite friendly atmosphere. The active engagement in the debate of women and some men with a family history of hereditary breast cancer, who wrote or told their personal stories to the media, may have helped solve the conflict. In this article, I identify the stories of suffering and the arguments for or against PGD that BRCA mutation carriers made public in response to the controversy. Subsequently, the empirical findings are interpreted in light of political theories on the role of storytelling in political discourse. Deborah Stone's recognition that storytelling is part and parcel of all political discourse and Iris Marion Young's analysis of what stories do are used to evaluate the transformative effect that the real-life stories had in the Dutch public debate on PGD for hereditary breast cancer.

Keywords Controversy, Democratic Debate, PGD, Politics, Stories

I didn't want to wait another few years. I was afraid and uneasy. As a prospective mother, you have to take responsibility. (Ellen Groenewold, BRCA mutation carrier, 25, waiting for PGD)¹

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¹ BRCA mutation carriers have a mutation in the Breast CAncer genes (BRCA-1 and BRCA-2 gene), which predisposes them to develop breast cancer, often before the age of 50.

Doesn't an embryo with a gene mutation have a right to live? I was once an embryo like that. I am alive and I am happy. (Esther Leeninga-Tijmes, BRCA mutation carrier, 30, history of breast cancer)

If you allow embryo selection for breast cancer, there will be plenty of other diseases to select for. There's no end to the list. That's why I am not for it. But I understand the problem. (Annie van der Horst-Van der Top, BRCA mutation carrier, 61, history of breast cancer, three adult daughters)

What are these politicians thinking when they tell people to accept an embryo with a gene defect? You consciously sentence people with a gene defect to an early death or severe illness. It is discussed without considering the actual women in question. (Jos Jansen, 56, BRCA mutation carrier, two affected daughters)

Embryo selection (preimplantation genetic diagnosis, PGD) for hereditary breast cancer is a hot item all across the globe. The debates are often polarized between advocates of embryo selection and opponents seeking to ban PGD altogether. Those in favour of embryo selection emphasize the principle of patient autonomy. In their view, female carriers of a serious hereditary disease should have the option of PGD to protect their children. Their opponents focus on the dangers of human enhancement. They use the *slippery slope* argument, i.e. since we are all genetically at risk for something, in the end barely anyone will rate being born. Some opponents argue that all human life, from its very beginning, deserves protection. Good health should not be a higher priority than human life itself.

In the Netherlands, the opposition escalated in May and June 2008, shortly after the State Secretary of Health wrote a letter to the cabinet proposing to rescind the ban on PGD for hereditary breast cancer. There was a clash between the Social Democratic Labour Party and the Reformed Christian Party, both represented in the Dutch Parliament. The political controversy was mirrored in the age-old moral issue of a woman's right to self-determination versus an embryo's right to life.

Surprisingly, the matter was ultimately settled in a quite friendly atmosphere. The contribution of a third group, i.e. women and some men with a family history of hereditary breast cancer who wrote or told their personal stories to the media, may have helped solve the conflict. In these stories, the principle of women's self-determination and the slippery slope argument appeared to be more ambiguous than either the Labour Party or the Reformed Christian Party were initially willing to acknowledge.

In this article, I evaluate the effect of personal, real-life stories on the Dutch public debate following the State Secretary's proposal to rescind the ban on PGD for hereditary breast cancer. Following Matthew Harvey's (2009) call to complement quantitative approaches for evaluating public deliberation with qualitative approaches that evaluate 'drama, talk and emotion', the analysis focuses on the first-hand experiences, emotions and opinions articulated by BRCA mutation carriers in response to the political controversy. Stories of lived experiences are said to evoke sympathy, promote mutual understanding and engender ambiguity. Political theorists disagree, however, on the role these stories should play in public deliberation. On the one hand, theorists like Iris Marion Young, Ruth Lister, Deborah Stone and Kathleen Jones call for inclusion of storytelling in political deliberation, since personal stories help to solve political

conflicts. They argue that stories enrich the democratic debate (Lister, 2003; Stone, 2002; Young, 1996). A political theorist like Seyla Benhabib (1996), on the other hand, argues that stories are more unsettling than helpful. As a member of the consultancy group who advised the State Secretary, I am concerned with how stories of lived experiences affect public deliberations about scientific issues that profoundly affect people's everyday life.

The analysis is qualitative and entails three steps. The *first* is to describe the political context of the controversy. The *second* is to identify the different stories of suffering and the arguments for or against PGD that BRCA mutation carriers brought into the public arena. The analysis draws on a literature search in the newspaper database Lexis Nexis, covering the period of 26 May to 27 June 2008, i.e. from the beginning to the end of the controversy. Data include all interviews with and letters from BRCA mutation carriers published in the large Dutch national newspapers (*AD/Algemeen Dagblad*, *de Volkskrant*, *Nederlands Dagblad*, *NRC Handelsblad*, *NRC.Next*, *Parool*, *Reformatorisch Dagblad*, *Trouw*), in regional newspapers (*Brabants Dagblad*, *Eindhovens Dagblad* and others) and in free newspapers (*Metro*, *Dag*)—altogether more than 40 articles.

A discourse analytic approach, in which the stories are considered to be part of a broader discourse, is used to identify the articulation of suffering by the BRCA mutation carriers and of their opinions about PGD, and to identify the transformative effect of the stories. Although the analysis appreciates the contribution of each individual BRCA mutation carrier, the focus is on the broader effect of the stories. The analysis proceeds from the following questions: What stories of suffering were told? What opinions about PGD were voiced? To what extent were the opinions related to the amount of suffering experienced? What messages did the stories convey? What effect did the stories have on the arguments of the other players and the course of the debate?

The *third step* is to interpret the outcomes of the empirical analysis in light of existing political theories on the role of storytelling in political discourse. The theoretical part of the analysis proceeds from the following questions: How to deal with different speaking styles in political discourse? How to understand the role of stories in democratic politics? What arguments do political theorists present to include or exclude stories from public life?

The *fourth step* is to use the theoretical outcomes to interpret the effect that the stories had, i.e. to better understand what the stories in this specific event did *do* in the public domain.

Context

PGD—also called embryo selection—has been performed in the Netherlands since 1995. It has been officially permitted since 2003 ‘if prospective parents run a heightened risk of having a child with a serious genetic abnormality or disease’ (Planningsbesluit, 2003). In 2007, this appeared to be too general a formulation for clinical geneticists, who felt more specific guidelines were needed, especially on severe hereditary cancers. Was it permissible to select for genetic mutations that predisposed fewer than 100 percent of the carriers to severe diseases? In addition, the Dutch Federation of Cancer Patient Associations asked the Ministry of Health to permit women with a heightened risk of a child with hereditary breast cancer to undergo PGD.

After consulting various experts, the State Secretary of Health wrote a letter proposing to rescind the ban on PGD for hereditary breast cancer. Her arguments in favour of PGD for hereditary breast cancer were grounded in the interests of future children (prevent suffering) and women considering PGD (advantages of PGD versus risks and distress related to PGD).

On 26 May 2008, the State Secretary of Health, a member of the Labour Party, announced during a television news programme that embryo selection for hereditary breast cancer would henceforth be permitted. The announcement was preceded by interviews with breast cancer patients recounting the disasters in their lives and families (Netwerk Television, 2008).

In the next few days, there was a storm of public protest. The Reformed Christian Party set the debate in motion. It publicly protested over the intentional creation of embryos, some of which would be selected and others destroyed. Permitting PGD for breast cancer would imply that it was better not to live at all than to live with a hereditary disease. The intrinsic value of embryos and the growing tendency to enhance human life but degrade *lesser forms* of human life were the Reformed Christian Party's main objections. In the words of Henk Jochemsen, an influential party adviser: 'Life, also the life of an embryo, conceals a secret that deserves respect' (Visser, 2008c). None of the Reformed Christian Party politicians explicitly mentioned their religious beliefs.

In the subsequent debate, the Labour Party underscored the principle of self-determination. BRCA mutation carriers should be allowed to have PGD to protect their children (see the Labour Party website: PvdA, 2008). The alternative of terminating the pregnancy after 12 weeks, as is allowed in the Netherlands if a child is carrying the BRCA mutation, was deemed a more drastic intervention than PGD.

Secular public leaders in support of the Labour Party accused Reformed Christian Party members of being fanatical fundamentalists who could not back up their arguments democratically and only answered to God (Ety, 2008). As a minority, it was argued, they wanted to impose their will on the rest of society. As well-known columnist Sylvain Ephimenco wrote: 'So these conservatives are able to impose their ideas on the rest of society and deny women access to progress and well-being' (2008). Other columns and editorials also accused the Reformed Christian Party of being tyrannical (*NRC Handelsblad*, 2008). Labour Party members publicly asked their party leader to leave the cabinet: 'You should no longer have to feel the whip of the Christians on your naked back' (Terstall *et al.*, 2008).

In response, the Reformed Christian Party accused the secular leaders of being intolerant, indecent and undemocratic (*Reformatorsch Dagblad*, 2008). As Reformed Christian Party leader André Rouvoet wondered at a party conference (*Nederlands Dagblad*, 2008): 'Does the debate stop and the scolding begin as soon as anything is said that is based on a Christian belief?' The seemingly insurmountable conflict was solved in about six weeks. The Labour Party and Reformed Christian Party both wanted to reach a compromise and thus uphold the governing coalition. Moreover, neither party wanted to fuel the public indignation about politicians trampling on women fated to live with hereditary breast cancer.

In response to the political controversy, quite a few women—and a few men—sent letters to newspapers or told their life stories to reporters. Between 26 May and the end of June, a good 40 letters from about 17 families and numerous interviews appeared in national and regional newspapers. Some carriers appeared on stage more than once. All

the interviewees recounted the distress their family had to face and gave their opinion on PGD. By describing their tragic dilemmas and showing the various ways they dealt with them, they challenged the self-determination argument as well as the one citing the growing tendency to enhance human life. I would like to first address the BRCA mutation carriers who were for PGD and then the ones who were against it.

Story contents I: Do they really know what living with cancer is like?

'I could kiss that State Secretary', exclaimed 36-year-old BRCA mutation carrier Caroline Haasbroek in a newspaper interview two days after the State Secretary proposed rescinding the ban on PGD for hereditary breast cancer. Haasbroek has had breast cancer, a mastectomy, chemotherapy and one ovary removed. The moment she heard her sister had breast cancer too, she knew one thing for sure: 'I would love to have children, but this disease should not be transmitted. It has to stop here' (Ligtvoet, 2008; Mat, 2008b; Noordhuis and Soest, 2008).

Like Caroline, 25-year-old BRCA mutation carrier Ellen Groenewold is hoping to have a child via PGD. Three years earlier her mother, who has had a breast amputated and has been treated with chemotherapy and radiation, was diagnosed with cancer for the third time. Ellen wanted clarity about her own status. When she found out she had the BRCA gene mutation, she opted for a preventive mastectomy. In the weeks after the television interview preceding the State Secretary's statement, several other reporters told Ellen's story (Groenewold, 2008; Lucas, 2008; Mee, 2008; Melchior, 2008; Netwerk Television, 2008).

Nicky Westerhof, a 26-year-old BRCA mutation carrier, recounted how she hopes to be the first carrier in her family to reach the age of 50. Her grandmother died a few months before her 50th birthday, her mother died at 46. Nicky has had a preventive mastectomy and said she would love to have children who are not affected (Netwerk Television, 2008).

In the weeks following the three women's request to allow PGD for hereditary breast cancer, many BRCA mutation carriers followed their example and told their stories in the national and regional newspapers. One of the claims the storytellers made was that Members of Parliament who were talking about them hardly had any idea what it meant to be part of a family with a history of hereditary breast cancer.

The problems facing carriers and their families and friends encouraged Brigitte Wesley, diagnosed with breast cancer and the mother of a teenager, to write in a national newspaper: 'Because of my experience, I am surprised at the Reformed Christian Party's point of view... Their theoretical, ideological and religious beliefs are diametrically opposed to the cruel reality... Do they really know what living with cancer is like?' (Wessely, 2008).

'The debate is not about me and other carriers', wrote Annemieke de Haan, a 37-year-old BRCA mutation carrier who had tested positive for the BRCA mutation a week earlier:

I have three daughters, 14, 11 and 8 years old. They have experienced from close by what it means to have cancer. They saw my sister's breast cancer, my nieces'... I myself am a Christian. I understand people who are against PGD as a matter of principle... But I want it and I take full responsibility for my choices. (Haan, 2008)

Jos Jansen, a 56-year-old BRCA mutation carrier, also drew attention to the politicians' lack of knowledge about the tragedies families are confronted with. His mother, grandmother and eldest sister have died of breast cancer. He himself has breast cancer; his youngest sister has ovarian cancer. His daughters (33 and 30), who are BRCA mutation carriers, have had preventive mastectomies and ovariectomies. In the interview, they called the way politicians discussed the issue 'inhuman' (Wissen, 2008).

'It feels like the sword of Damocles. My life is worth living, but at the same time it is tough and uncertain', said Emma van Leeuwen, a 40-year-old BRCA mutation carrier. Her mother died of breast cancer. Emma was pregnant with her second daughter when she discovered that her mother had the BRCA mutation. 'If I had known before my pregnancies that I am a carrier, I would certainly have considered PGD' (Visser, 2008b).

Anny van Daalen, a BRCA mutation carrier also in favour of embryo selection, wrote: 'After I had cancer, both my breasts were amputated. Although it was quite some time ago I still have the sense of it being medieval' (Daalen, 2008).

Marijke, a 62-year-old BRCA mutation carrier, whose breasts, ovaries and uterus have been amputated, shared this view. Marijke has two daughters (36, 33), one son (31) and has several grandchildren. She is Catholic and 'sure the Lord would approve of preventing the birth of severely handicapped or diseased children' (Brand, 2008).

Christien is a 30-year-old BRCA carrier. Her mother died of breast cancer, her sister had breast cancer and she herself has had breast cancer, a mastectomy and chemotherapy. She has the most resolute opinion about her family history. She became pregnant via PGD in Belgium. 'The rest is history', she declared, proudly rubbing her bulging belly (Schalkwijk, 2008).

Story contents II: The value of a life with cancer

However, understanding the problems facing BRCA mutation carriers was not the same as agreeing to rescind the ban on PGD. In response to Ellen, Nicky and Caroline's public call to understand their wish for PGD, there were also BRCA mutation carriers with a very different view.

'I follow the news on embryo selection with growing amazement', said 30-year-old mother Esther Leeninga-Tijmes in a national newspaper. 'Does life no longer have any value if you have a gene mutation that increases the risk of cancer?' She developed breast cancer at an early age. She was cured after a mastectomy, chemotherapy and breast reconstruction. Her grandmother, aunt and cousin died of breast cancer.

In the beginning, the thought that my daughter might have the gene mutation was almost unbearable. Now I understand that twenty years from now, the treatment of cancer might be much better. I was strong enough to handle breast cancer, and she will be too.

After her experience with breast cancer, she wondered whether women who opted for PGD knew enough about the options available to prevent and treat breast cancer (Visser, 2008a).

Margriet Kruijver, a 51-year-old woman who has had breast cancer, shared Esther's belief that a life with a gene mutation is no less valuable than a life without it. 'Who could

dare decide that a life like mine, so expansive and rich in experiences, is better not lived because of the cancer?’ (M. Kruyver, 2008). Her father, a gynaecologist, did not share her point of view. In a letter to *de Volkskrant*, he wrote: ‘If I had not made it as an embryo, by definition I would not have cared. A more beautiful or smarter brother or sister could have been born, who might have lived a happier life. Since I was already there, they did not come’ (G. Kruyver, 2008).

Louise van Rossum, a 56-year-old BRCA mutation carrier, the mother of two adult children, felt one should love an affected child a little extra. In a long interview in a national newspaper, she said she and two of her three sisters are BRCA mutation carriers. One of her sisters had had breast cancer at the age of 28 and died two years later. Louise and the other sister had had preventive mastectomies and ovariectomies. Embryo selection had not been an option yet when Louise wanted children. In retrospect, however, she is quite sure she and her husband would not have opted for PGD. ‘It wasn’t easy to become pregnant, and we agreed that we didn’t want to use all kinds of artifices. If you opt for embryo selection you cannot avoid that; an IVF procedure is always required.’ When they talked about embryo selection, Louise’s daughter brought up the argument of enhancement. ‘She said she didn’t understand why people do that. They only want a healthy child, a child there is nothing wrong with’ (Mat, 2008a).

Annie van der Horst-Van den Top, a 61-year-old BRCA mutation carrier and mother of three adult daughters, had the same opinion. ‘If you allow embryo selection for breast cancer, there will be many other diseases to select for. There’s no end to them.’ She has had breast cancer in 1990 and 2004, her eldest sister died of breast and ovarian cancer and her youngest sister has breast cancer. She experienced the anguish, but firmly believes her life is in God’s hands: ‘I can just let it go’ (Noordhuis and Soest, 2008).

The same held true for Catrien van den Berg, a single 46-year-old BRCA mutation carrier, whose mother died of breast and ovarian cancer. She has had a preventive ovariectomy and has regular preventive breast check-ups. ‘I am always calm if I have to be checked at the hospital. God is my source of power.’ It frightens her to know she might not have been born if embryo selection had been possible at the time (Noordhuis and Soest, 2008).

Marijke, a 30-year-old BRCA mutation carrier interviewed by the same reporters, is ‘absolutely against embryo selection’ because she believes we should not select human life. She has had a preventive mastectomy and has two daughters. She does not want to criticize women who chose not to have children because of what they had experienced, but selection is unthinkable for her (Noordhuis and Soest, 2008).

Am Schüngel, 67 years old, was also familiar with the anguish. Her mother, her daughter and she herself had had breast cancer. Her mother had survived after having her breast removed and lived to be 85. Am was 37 when her breast cancer was discovered. It was in an advanced stage and the physicians didn’t give her much hope. But she recovered after a mastectomy. Her daughter also developed breast cancer at the age of 37. She made it thanks to breast-saving surgery, chemotherapy and radiation. None of them opted for genetic testing and embryo selection. Their main reason was their aversion to the idea of malleability. In Am’s words: ‘It is not a law that you will get breast cancer. I find genetic research so calculative, it turns your life into a sad life’ (Bles, 2008; Schüngel-van der Haar, 2008).

Pieter Klok, possible BRCA mutation carrier, was hesitant to be tested, especially since his wife is expecting their third child. In his father’s family, almost all the women died

around the age of 45. He had received a letter in 2006 telling him hereditary breast and ovary cancer ran in the family. He spoke to medical experts, juggled with statistics, and ultimately decided not to talk about it for at least 16 years. But then he saw a woman on television demanding the right to have her embryo tested. Should he, a sensible person and potential BRCA mutation carrier, do the same? After pondering for days, his best friend tried to imagine what it would be like to be Pieter's offspring. 'If they told me I was allowed to live, but my penis would be amputated at the age of 18, I would say: let me live. Sure. Life is much too beautiful, isn't it?' That was a good reason for Klok to decide not to have a test. 'The only thing I hope is that all my children love life as much as my friend' (Klok, 2008).

Understand that you do not understand

It is quite unusual for so many people to pick up a pen and tell their life stories in response to a political conflict.² Carriers of the BRCA mutation must have felt the urge to demonstrate to politicians and people in general the uncommonness of their situation. One of the messages in the letters and interviews was that most people, politicians included, have no idea what it is like to live with hereditary breast cancer.

The politicians' arguments for and against PGD appealed to the world to avoid or accept human suffering, but the unique life stories of the BRCA mutation carriers showed what the suffering entails. The stories provide social knowledge about the effects of the ban on PGD on families with a history of hereditary breast cancer.

The carriers' stories help people who do not have to live with hereditary breast cancer understand what they are facing. Simultaneously, the narratives show that, virtually by definition, this understanding is limited. Understanding means that non-affected people understand they cannot really understand what it is like to be part of a family with hereditary breast cancer. They cannot share the experiences of the carriers. The stories are inspired by frustration about how people do not seem to realize what carrying the mutation means. 'Unbelievable, that people say carrying the mutation is not so bad', Ellen remarked indignantly (Mee, 2008). Her story evokes sympathy, but keeps others at a distance. By doubting whether politicians can really know who she is and telling her own personal story, she revealed experiences that cannot be shared by those who are not genetically at risk but still need to understand her situation in order to do her justice.

By emphasizing the exceptionality of their condition, the first group of BRCA carriers challenges the slippery slope argument, i.e. if we allow PGD for hereditary breast cancer, we will also take the next step and allow PGD for all kinds of other diseases and abnormalities. In some cases, being a BRCA mutation carrier is as bad as carrying the gene for Huntington's disease, in which case carriers are almost 100 percent sure they will develop the disease, they just do not know when. The story of 25-year-old Nicky, who hopes to be the first in the family to reach the age of 50, is comparable to stories of Huntington's

2 In their review of the relationships between science and citizenship, Melissa Leach and Ian Scoones argue that citizenship as engagement with scientific controversies, where citizens bring their own experiential expertise to bear, may now be 'a key context where citizenship practices are played out in new, important ways' (2005: 31).

gene carriers. The problems she has to face are different than those of 67-year-old Am Schüngel, whose mother reached the age of 85. Some women with a family history of breast cancer have seen many of their relatives die of the disease. They feel offended by the claim that not wanting your relatives to die of breast cancer at an early age is a form of human species enhancement.

A second message the stories convey is that each story is unique. The story of Jos Jansen, whose mother, sister and grandmother had died of breast cancer and who knows he has transmitted the gene mutation to his daughters, is entirely different from the story of Pieter Klok, whose children have about a 12.5 percent risk of being a carrier. Continuing the ban on PGD means treating all the cases the exact same way, even though the stories make it poignantly clear how different they are. Having breast cancer in your 20s is not the same as having it in later life. Having relatives who survived breast cancer is not the same as losing your mother, sister and other female relatives to breast cancer. Having breast cancer before childbearing is not the same as having it afterwards.

A third issue the stories are clear about is that knowing one of the prospective parents is a BRCA mutation carrier puts couples in a tragic dilemma. Whatever they decide, the outcome will not be what they want. They could decide not to have children, thus reducing the risk of vertically transmitting the mutation to zero. This means childlessness. They could opt for pregnancy, undergo prenatal testing and have an abortion in the event of a demonstrated BRCA mutation. This means the termination of a wanted pregnancy. They could decide to conceive a child via IVF and PGD. The physical and psychological stress this intervention entails are enormous and the chances of success limited. They could decide to take the risk of vertically transmitting the BRCA mutation and not undergo prenatal testing or PGD. In this case, the unwanted effect would be that half their children might be affected by the mutation.

When there was no genetic testing for BRCA mutations, it was understandable that people just had children. Until the 1980s, there was barely any awareness of the link between cancer and heredity (Snelders *et al.*, 2007). Moreover, it is only since the 1960s that almost perfect contraceptive methods have been available. Since the 1990s, when BRCA tests were introduced, public awareness of the genetic aspect of breast cancer has increased immensely. The awareness that breast cancer could be inherited confronted women with breast cancer in the family with a responsibility previous generations had not experienced.

Knowing that one has a transmittable gene mutation inevitably leads to the normative question: Are you allowed to transmit the mutation to your children? It makes people responsible for the future health of their offspring. The culturally highly valued principle of patient autonomy underscores this responsibility. 'As a prospective mother, you have to take responsibility', as Ellen Groenewold commented. Jos Jansen also raised the question of responsibility, but more in relation to the past than the future. He feels guilty about being the one who has transmitted the gene defect. He knew he could not be blamed, but still saw himself as the source of the misery. Even potential carrier Pieter Klok, who did not get tested, felt his responsibility. Knowing breast cancer runs in the family and he might be a carrier and transmit it to his children was enough reason to feel responsible for his progeny.

One last, striking thing the stories show is that there is no simple correlation between the life stories of BRCA carriers and their opinions about PGD. Young carriers are for and against it, as are older ones, women with children, women without children, men, religious

carriers and non-religious carriers. The only factor that might have played a role in how carriers felt about having PGD is the extent to which they experienced the disaster in their family. Even those on the sidelines understand that Nicky wants to stop the disease whereas Am quietly accepts living with it.

Stories and democratic ideals

The Netherlands is an old, quite stable democracy with an electoral system of proportional representation. It has a long tradition of reaching decisions by consensus (Dahl, 2000: 119, 136, 153). In this perspective, everyone's active participation in political deliberation is thought to be vital to the survival and further development of the democracy. People are encouraged to come together or meet politicians to talk about collective problems, ideals, aims and actions. But how to deal with their different speaking styles? Does a modern-day theory of democracy need a broad and plural conception of communication, including storytelling, as political theorist Iris Marion Young suggests (1996: 132–133)?

Young promotes a theory of *communicative* democracy in which differences in culture, perspective and interest are taken as starting points. She distinguishes communicative democracy based on differences and *deliberative* democracy based on shared understanding and a common good. In deliberative democracy, discussion partners ideally value the common goal above their own experiences and interests. Young argues that if you ask participants not to consider their own experiences and interests, the perspectives of the privileged are likely to dominate (1996: 127), and the opportunity to learn from the experiences and ideas of others is lost.

Following Hannah Arendt's view that plurality is the condition of all political life (Arendt, 1998: 7), Young describes communicative democracy as a process of mutual expression of experiences and ideas, in which people aim to transcend differences, thus reaching mutual understanding. In Young's words:

The ideal of communicative democracy ... recognizes that when political dialogue aims at solving collective problems, it justly requires a plurality of perspectives, speaking styles, and ways of expressing the particularity of social situations as well as the general applicability of principles. A theory of democratic discussion useful to the contemporary world must explain the possibility of communication across wide differences of culture and social position. (1996: 132)

Young considers greetings and rhetoric as well as stories to be important means of expression that help people communicate differences. Stories foster understanding across differences, reveal particular experiences of people in different social contexts, evoke sympathy for the particular situation and experiences of others, explain to outsiders why insiders value what they value, and reveal a total social knowledge from the point of view of insiders. Narratives can play an important role in democratic discussions, Young maintains. They help people transcend differences and conflicts and do justice to everyone involved. 'Storytelling complements arguments in a communicative democracy because it tends to be more egalitarian than typical deliberative processes' (Young, 1996: 132).

In her book *Citizenship: Feminist perspectives*, political theorist Ruth Lister uses a similar argument to include informal speaking styles, especially of women, in politics. Referring

to feminist theorist Kathleen Jones, she argues that for policies to be friendly to women and the multiplicity of their interests, a democracy has to be rooted in the experiences of women and transform the practice and concept of citizenship to fit these varied experiences (Lister, 2003: 166).

This idea of re-articulating the relationship between formal and informal politics has been challenged by political theorist Seyla Benhabib. In a critical response to Young, she states that as an aspect of informal communication in everyday life, storytelling should not become part of our formal public reasoning. Stories bring the particularity, embodiment and subjective experiences of individuals into the public arena, where they can be seen and heard by everyone. In her view, opening up formal discourse on politics and law to informal modes of communication would induce arbitrariness and limit, rather than enhance, social justice, since storytellers are not asked to render an account of their story on the basis of what is commonly valued or agreed upon (Benhabib, 1996: 83). Like Jürgen Habermas (1996a, 1996b), Benhabib supports a deliberative model of politics, in which opinions are formed and decisions reached through communicative processes that allow the better arguments to come into play (Huijjer, 2003). Better arguments are those that appeal to commonly shared and accepted public reasons—a position that has been critiqued by many for being too extreme or too idealistic (Fraser, 1992).

Young, Lister and Benhabib distinguish between rational deliberation and formal modes of politics on the one hand and storytelling and informal modes of politics on the other. However, political theorist Deborah Stone presents a model in which the boundaries between these two modes of politics are blurred.

In her book *Policy paradox*, Stone argues that almost all definitions of policy problems have a narrative structure. Political arguments are ‘stories with a beginning, a middle and an end, involving some change or transformation’ (Stone, 2002: 138). Politicians tend to tell decline, helplessness-and-control, or blame-the-victim stories. These narratives are used to explain what the world is about, and what we have to do to solve our problems.

Stone’s recognition that storytelling is part and parcel of political discourse does not mean that all stories are equal. Some are more ambiguous than others, she writes. She feels that ambiguity is essential in politics because it enables individual strivings to be transformed into collective aims and decisions. Ambiguity provides opportunities for change and helps people overcome political conflicts. Unambiguous types of politics, however, are of little use in the real world. ‘Without ambiguity, cooperation and compromise would be difficult, if not impossible’ (Stone, 2002: 157).

Her analysis of the narrative structure of all political discourses, combined with her distinction between ambiguous and unambiguous stories, may help us understand the role stories played in the discussion on PGD.

Following Stone, it is clear that the Reformed Christian Party contributed to the discussion with a story of decline, i.e. a slippery slope story. ‘Things have gone wrong, and if we don’t do anything, a disaster will follow.’ The Labour Party, in turn, favoured a story of helplessness and control. ‘The situation for couples with hereditary breast cancer is dramatic. We always thought these couple were helpless in shaping their fate. But now let us show you how we can help them.’ In the discussion on embryo selection, these political narratives were used to explain what PGD is about and how we should or should not deal with it. Each of the parties tried to win the argument by telling a clear-cut, unambiguous story.

The personal stories the BRCA mutation carriers introduced into the discussion on embryo selection were more ambiguous than those of the politicians. The main issue in their stories was not how to decide for themselves or prevent a move towards the slippery slope, but how to deal responsibly with the severe suffering they witnessed in their family or experienced personally—a finding congruent with other studies on genetic risk and responsibility (Hallowell, 1999). Their stories consisted of many story lines with different beginnings, middles and endings. Rather than providing simple answers, they emphasized the moral complexity of the situation. A clear plot was often lacking. Moreover, their style of speaking was more emotional and less rhetorical, it was more aimed at reaching understanding than persuading others.³

Following Young's analysis of what stories *do* and Stone's analysis of the relevance of ambiguity, we can conclude that, via their ambiguity, the stories fostered understanding, evoked sympathy for the particular experiences of BRCA mutation carriers, and revealed a more comprehensive social knowledge of hereditary breast cancer from the carriers' point of view. The stories had the power to complement and open up the arguments used in the PGD discussion. Via their ambiguity, the stories transformed individual views into collective affairs. They helped transcend the controversies about PGD and take the interests and experiences of everyone involved into account.

But . . .

But how can we be sure stories evoke understanding of a specific situation? Do stories really help to solve political conflicts? What if people did not understand the BRCA mutation carriers' stories? Stories have a place within the informal communication of everyday life, but that is no reason to make them part of our public life, as Benhabib says (1996: 83). Her argument is challenged by the BRCA mutation carriers' stories. If they had not made their unique life stories public, people would never have understood what living with a BRCA mutation meant. Some experiences have to be made public so everyone will know.

Making stories part of democratic communication or deliberation has also been criticized because of the emotions aroused by stories, emotions that can interfere with the rationality political issues and conflicts call for. In the case of BRCA mutation carriers, opponents of PGD for hereditary breast cancer complained that the compassion elicited by the stories of young female carriers who wanted a child via PGD undercut the rational deliberation on the issue. Their complaint would have been convincing if the readers and viewers had not been able to evaluate the emotions the stories evoked. No doubt the hardships alluded to in stories affect our emotions, but this does not keep us from evaluating the rationality of these emotions. If emotions are intelligent responses to what we value or deem important, as Martha Nussbaum (2001) claims, it is understandable that the exceptionality of specific hardships, as expressed in the stories, affects our reasoning. This exceptionality could be an argument to allow PGD for hereditary breast cancer. But the willingness to

3 In a UK study on media representations of inherited breast cancer, Henderson and Kitlinger (1999: 74) also observed that personal stories of women with inherited breast cancer introduced soft values, uncertainty and 'shades of grey'.

live with the hardships also expressed by BRCA carriers could also be a reason to continue the ban on PGD. Moreover, emotions not only generate new, unheard arguments or perspectives, they also interact with arguments. The television discussion between BRCA mutation carrier Caroline Haasbroek and Reformed Christian Party adviser Henk Jochemsen is a good example (NOVA/Den Haag Vandaag, 2008).

But how do we know powerful interest groups like the Federation of Cancer Patient Associations or politically biased journalists did not manipulate the stories? BRCA mutation carriers Ellen Groenewold and Caroline Haasbroek are eloquent women who, supported by clinical geneticists and a growing number of female journalists, took the opportunity to voice their wishes in various media. As Henk Jochemsen, advisor of the Reformed Christian Party complained: 'The advocates of embryo selection, especially the media, were too quick to put the patients in the limelight' (Visser, 2008c). This assertion would wash if journalists had deliberately recruited BRCA mutation carriers desperately seeking PGD. Or if BRCA mutation carriers had made a collective effort to defend their interests. However, our survey of the letters and interviews shows that this was not the case. Many carriers were not interviewed at all, they wrote their own letters to the media. They usually did so individually. Moreover, the media also recorded the stories of carriers who were against PGD for hereditary breast cancer. The manipulation argument does not hold. In the wide range of stories and the ample participation, the storytelling of the BRCA carriers presented a representative picture of what it is like to live with hereditary breast cancer.

Effects of the stories

At the end of June, the State Secretary of Health wrote a second letter on PGD. This time it was the outcome of the consensus reached by the parties in the cabinet (Labour Party, Reformed Christian Party and Christian Democrats). The letter stated that one of the main cabinet aims was to do justice to the complexity of the individual cases. In addition to the values of patient autonomy and embryo protection, good care was cited as an important value. 'Good care means caregivers focus attention on the patients' needs and interests by surrounding them with professional care, providing understandable information and specifying the possible consequences and risks of treatment' (Bussemaker, 2008c: 6).

The initial effort to formulate an inventory of diseases PGD would be allowed for was replaced by a set of criteria and each request for PGD was to be separately evaluated. Assisted by a multidisciplinary team of experts, in each case the patient and physician are to take into account the severity and nature of the disease, the treatment options, additional medical criteria, and psychological and moral factors.

The careful application of these criteria makes it possible to allow PGD for couples who wish to have a child without the severe genetic disease threatening them and their families. It also helps keep the application area from shifting to patients with no high individual risk of hereditary diseases' (Bussemaker, 2008c: 9).

It is striking that this formulation does justice to the needs and interests of BRCA mutation carriers as formulated in their stories as well as those put forward in the Reformed Christian Party's slippery slope argument and the Labour Party's call for patient autonomy.

The Reformed Christian Party was satisfied because the inventory of diseases embryo selection would be allowed for was replaced by a set of meticulous criteria, guaranteeing that the focus of health care would stay on treatment and cure rather than on selection. ‘The feared slippery slope is a thing of the past’, the party wrote (Christen Unie, 2008). The Labour Party was satisfied because the options for embryo selection, and thus women’s autonomy, were expanded (*NOS Journaal*, 2008).

Although it is hard to know what exactly inspired this broader, subtle and sensitive phrasing, the stories of the BRCA mutation carriers undoubtedly played a role. In the weeks after the controversy started, the Reformed Christian Party and Labour Party both felt called upon to respond publicly to the stories of the BRCA mutation carriers. Via Jochemsen, the Reformed Christian Party stressed that it ‘did not want to overlook the suffering of these women. It is terrible what they have to face’ (Visser, 2008c). Party leader Rouvoet told his audience at a party conference that the Reformed Christian Party’s favourite part of the car was not the brakes but the steering wheel, and that the party aims to give developments a push in the right direction (*Nederlands Dagblad*, 2008). State Secretary Bussemaker (Labour Party), in turn, said afterwards that in reaching a compromise she not only had to take into account the BRCA mutation carriers who vehemently hoped for embryo selection, but also the carriers concerned that they would not have been alive if embryo selection had been allowed before (*Eén Vandaag*, 2008).

In sum, after listening to the ambiguous stories of women and men who had directly experienced the anguish of living with hereditary breast cancer, the unambiguous and principled way the Labour Party and Reformed Christian Party started the public discussion on PGD for hereditary breast cancer came across as disrespectful. The stories helped to transform the public sphere, where politicians and the public generally act and speak, into a realm where people were prepared to listen to each other and reach mutual understanding.

Conclusion

Political decisions related to issues of life and death can have a profound impact on individuals’ everyday lives. Active participation of citizens in the political deliberation of these issues is therefore deemed important. It is not clear, however, how to appreciate and evaluate in this process the emotions and experiences brought into the public space by people who are directly affected. Stone’s claim that storytelling is part and parcel of political discourse, and that some stories are more ambiguous than others, and Young’s analysis of what stories *do* are used to explore the transformative effect that stories may have on political controversies.

The Dutch debate on PGD for hereditary breast cancer shows that when individuals who are directly involved present their unique life stories to the public, a fierce debate can change into a more relaxed mode of communication, where arguments as well as stories and emotions have a place. Storytelling can transform the public realm into a locus where collective problems are solved by opening up the ambiguities in each other’s positions.

In this specific case, the stories of the BRCA mutation carriers made everyone taking part in the debate feel confident because the women and men involved appeared to be very aware of the possibility of the slippery slope as well as the responsibility placed on their

shoulders. In some cases, the responsibility for the health of their children was reason enough to opt for PGD, in others the fear of the slippery slope was a reason to forego prenatal testing and embryo selection. The stories demonstrate that allowing PGD would not lead to a situation where couples easily opt for embryo selection. On the contrary, more than any reasoned argument, the stories of the carriers demonstrate the moral complexity of their situation. In a democracy where most political leaders and private citizens prefer clear-cut positions to ambiguity, that is a huge accomplishment.

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