

Patients' Views On Using Human Embryonic Stem Cells To Treat Parkinson's Disease - An Interview Study

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Abstract

Background: Human embryonic stem cells (hESC) as source for the development of advanced therapy medicinal products (ATMP) are considered for treatment of Parkinson's disease (PD). Research has shown promising results and opened an avenue of great importance for patients who currently lack a disease modifying therapy. The use of hESC has given rise to moral concerns and been the focus of, sometimes heated, debates about the moral status of human embryos. Approval for marketing is still pending.

Objective: To investigate the perspectives and concerns of patients with PD, patients being the directly concerned stake holders in the ethical discussion.

Methods: Qualitative semi-structured interviews related to this new therapy in seventeen patients from two Swedish cities.

Results: The participants expressed several interests related to the use of human embryos for development of medicinal therapies but were overall positive to the use of hESC for treatment of PD.

Conclusion: It was important that the donating woman or couple are donating embryos voluntarily and there was a worry that the industry does not always prioritize the patient over profit and transparency is therefore seen as important.

Introduction

Human embryonic stem cells

Human embryonic stem cells (hESC) are undifferentiated, pluripotent cells derived from the inner cell mass of a human blastocyst at approximately less than a week. Long before the first hESC lines were generated in the 1990's [1], researchers have seen the potential benefit of using hESC from embryos in the pre-implantation phase in regenerative medicine. The abilities of hESC to differentiate into any specialized cell, together with their capacity to self-renew, have raised hope of them being able to replace damaged cells and tissues, and being useful in treatment of various diseases.

The use of hESC have raised moral concerns

The moral status of the human embryo is a long-standing controversy thoroughly debated over the years. The ambiguity of this status of the embryo, has led to controversies without reaching consensus [2]. Whether, and to what extent, the human embryo has a moral value that deserves protection or not, is repeatedly discussed alongside the medical development [3]. As more about cells and their potential is learned through medical research, the perceptions concerning the embryo, and the question of when human life begins, have been challenged. During last decades, this issue has become perhaps more relevant than ever, as medical advances have shown that the embryo in the pre-implantation phase

potentially could be used as a mean in producing medicinal products, to benefit patients and increase their health.

Human embryos are generated in regular medical practices for reproductive purposes for IVF procedures. Since the first successful IVF procedure, approximately 8 million IVF children have been born, and at any given time point it is estimated that more than 500.000 embryos are being kept frozen awaiting IVF procedures. After successful IVF procedures there are embryos frozen that are no longer considered for reproductive purposes. These latter embryos are considered for medical research or are destined for destruction [4].

In previous research regarding moral concerns of using human embryos for non-reproductive purposes IVF couples have described the cryopreserved embryo as a human being, a (potential) child or a sibling to already existing children [5, 6, 7], and that it is callous to use it for such purposes [5, 8]. A Swiss study from 2009 investigated the attitudes of IVF-couples towards the moral status of the embryo and it showed that 50% agreed that an embryo has the same dignity and rights as a human being [7]. Another study has shown that some consider their cryopreserved embryos being too private to give away [9]. People assigning embryos high moral status are less inclined to donate their embryos for research purposes [10]. There are concerns what will happen to the donated embryos, that the embryos will be misused or will be used to do “bad” things [5, 6]. Previous studies show that 27–92% of couples donate or are positive to embryo donation for stem-cell research [11]. In one year, as many as 92% of the couples at one Swedish IVF clinic consented to donate their surplus embryos for stem-cell research [12].

In contrast, embryos are also described as “just a ball of cells” with no moral value, or that they gradually gain moral value as they develop [2, 7, 13]. According to this view, it may be acceptable to use hESC to produce ATMPs. In previous studies, positive attitudes to embryo donation are justified by the interest of helping others, making good use of embryos that otherwise would be discarded, wanting to give back to the society after having received medical care themselves, and wanting to contribute to medical advances [5, 8, 9]. A positive attitude to embryo donation is associated to disagreeing that the embryo has the dignity and rights of a human being [7]. Some describe they do not want to waste the embryos or the efforts needed to create them [14].

To our knowledge, there are no previous studies investigating patients’ views as potential receivers, but three studies have studied attitudes to embryo donation specifically for medical treatment some years ago. The studies are performed on couples having undergone fertility treatment in China, Denmark and Switzerland. They show that 26 to 41 percent were positive to donating embryos for treatment purposes themselves [15, 16] or that embryo donation should be allowed [7].

Induced pluripotent cells are not surrounded by the same moral issues as hESC

In parallel with the development of ATMPs using hESC, researchers have succeeded in producing induced pluripotent stem cells (iPS-cells), [17] from human cells and are using them for medical development.

Unlike hESC, iPS-cells are derived from non-germ cells and thus not surrounded by the same moral concerns.

The potential use of hESC and iPS cells in treating Parkinson's disease

Researchers are currently developing medicinal products to replace damaged or dead cells for various chronic diseases, e.g. for Parkinson's disease (PD). As for now, the etiology of PD is still unknown. There are no disease modifying therapies available for patients but therapy focuses on symptom relief by compensating for low brain dopamine levels. Commonly, patients' daily lives are increasingly affected over time by symptoms such as tremor, slow movements and balance problems. It is common to develop non-motor problems like depressive symptoms and later dementia. As the symptoms get worse with time, medicines are often given more frequently and device-aided therapies are introduced. It is not uncommon that patients suffer from side-effects of treatment, such as dyskinesia or behavioral problems.

In summary, there is a lack of knowledge concerning values and preferences related to embryo donation for development of medical therapies. We have not identified any studies investigating patients' attitudes, as potential receivers, to embryo donation for production of ATMPs. To this day it is still unexplored what patients with PD think of medical treatment developed from hESC. Since they are significant stake holders in the moral discussion presented, their view on the matter is arguably of great interest in itself, but also for policy makers and legislators.

Aim

The aim of the study was to explore the views of people with Parkinson's disease (PD), on using hESC for treating PD.

Definitions used:

Embryo – the early stage of development of an organism. For humans the term encompasses the period from fertilization to the end of organ formation, at week 9 after conception.

The embryonic period is further divided into one pre-implantation phase up to 5 days after fertilization, when the embryo can be held in culture, or kept frozen.

Pluripotent embryonic stem cells develop in the inner cell layer of a blastocyst and can be retrieved from this phase.

After implantation into the uterus embryos are generally not considered for medicinal purposes.

An embryo has no ability to survive outside of an uterus and all organs have not yet been formed.

Materials And Methods

Design

The study was a qualitative semi-structured interview study.

Settings

In Sweden is it legal to use human embryos for research purposes but not to produce medicinal products. As of 2019, couples undergoing fertility treatments are allowed to cryopreserve their embryos for a maximum of 10 years before they are to decide what to do with their surplus embryos. Surplus embryos can be discarded, donated to research, or donated to other couples and single women for reproductive purposes.

Participant selection

Participants were consecutively sampled through two local PD patient organizations located in two Swedish cities. The heads of the patient organizations shared information about the study to their members (N = 377) by email and any persons interested in participating or had questions regarding the study were asked to contact the researchers. Seventeen individuals (4.5%) contacted the researcher, accepted participation and were interviewed, with no drop-outs. The participants were Swedish-born, had a mean age of 68.6 years (SD 9.6 years) and about two thirds were male. They described their own religious background as Christian, non-religious, Evangelical, or atheistic. Additional participant characteristics are presented in Table 1.

Table 1
The characteristics of the participants (n = 17) presented with frequencies and percentages or mean (M) and standard deviation (SD).

		<i>n</i> / <i>M</i>	% / <i>SD</i>
Gender	Female	5	29.4
	Male	11	64.7
	Other	1	5.9
Age		68.6	9.6
Born in Sweden		17	100
Occupation	Working	5	29.4
	Sick leave	2	11.8
	Retired	11	64.7
Completed level of education	Upper secondary school	4	23.5
	Higher vocational education	2	11.8
	College / University	11	64.7
Use of medication	Daily	17	100
Time since PD diagnosis	6–12 months	1	5.9
	1–3 years	4	23.5
	3–5 years	3	17.6
	5–10 years	5	29.4
	10–15 years	2	11.8
	15–20 years	2	11.8

Data collection

Due to the covid-19 pandemic, the interviews were performed by telephone. The participants were free to participate from the location they preferred. Before the interviews, respondents received a detailed information material about hESC and the potential treatment for PD. Informed consent was given by the participants and they were asked to respond to a brief online-questionnaire concerning their background characteristics. An interview guide was used for the semi-structured interviews (Table 2).

Table 2
Interview guide used for the semi-structured interviews.

• Can you please tell me what experience you have of medical treatments against Parkinson's disease? (warm-up question)
• Have you previously heard of medical treatments using cells taken from embryos?
• If you think of when you first heard of medical treatments using cells from embryos, what were your first spontaneous thoughts?
• What is your view on using embryos for treatment of Parkinson's disease? That donated embryos are destroyed in the process? That companies may profit from selling these medicinal products?
• In this question, what is important to you? Interests/values? To whom?
• What affects your outlook on this matter, do you think? Any beliefs?
• If you reflect on what you have told me so far, what aspects are most important to you concerning using surplus embryos to treat Parkinson's disease?
• Have you changed your view on this matter during the interview?
• [Interviewer sums what the participant has described so far]. Have I misinterpreted something, or do you want to add something to the summary?
• The purpose with this interview was to explore your view on using donated embryos for medical treatment and any values or interests related to it. Is there something you think of that has not been brought up yet?

The interviews lasted between 32 and 105 minutes, with a mean of 58 minutes. Data collection was performed after approval was obtained from The Swedish Ethical Review Authority (Dnr 2019–06539).

Analysis

The interviews were transcribed verbatim and analyzed by three of the authors (JD, JVJ, EJ). The analyses were performed inductively using thematic content analysis, according to Burnard et.al. [18]. Shorter and longer text segments in the interviews were coded openly by writing in short what was being said by the participant. JD coded all interviews while JVJ and EJ coded five interviews each. One of the interviews was separately coded by all three and eight interviews were coded by two of the authors. The codes were compared, and differences were discussed and agreed upon. A list of all the codes was compiled, duplicates were removed, and similar categories were grouped together.

Results

Three themes emerged while performing the analyses: Factual beliefs and moral concerns related to the human embryo; moral positions concerning the use of hESC for medical treatment; and interests related to the use of hESC for medical treatment.

The factual beliefs and moral concerns related to the human embryo

The philosophical question of when human life begins was described as decisive for their opinion for what purposes human embryos should be allowed to be used. It was seen as impossible to reach consensus in society on when life starts. There were different perceptions of the moral status of the embryo. The embryo was described as being a mere lump of cells with the same value as any other cells. During the interviews, participants also likened the embryo to organs and germ cells. The embryo was by some described as having no life. Thus, no life is ended and no one is hurt when embryos are perished. It was also described in terms of what it does not constitute; it was not seen as a child or a human being. One person described that it is no life as the embryo lacks sensation. However, it was also looked at as something special and as potential life. The human embryo was also seen as a resource, a resource that is constantly produced in abundance. While some were firm in their perceptions, others showed ambivalence and at times described the human embryo inconsistently. Some explained they would have had a different view on the embryo if the embryo was inside the womb or if it was older.

The embryo was ascribed no certain value and was not seen as something special by some participants.

“Uhm in some way, if I would have had it in, I mean if it was split in two fractions [...] a tube of sperm wouldn't be that exciting.[...] But I am not convinced that it is much more exciting with a tube of eggs, and I am not convinced it is much more exciting if you mix them together. [...] It becomes something else along the way, from being implanted and then ,uhm, becomes a fetus, but when it is in the tube. [...] The difference is not that dramatic, I mean.” (Participant 17)

Some ascribed the embryo its value based on whether it later will become a human being or not. The embryo was considered to be highly valuable to the couple trying to achieve a pregnancy using them, as the embryo has the potential to become their child. However, when the embryo becomes superfluous, and the couple is not any longer in need of it, its value was described as instrumental or a mean that could be useful for other purposes, such as helping others. The embryo was described as a valuable resource or a material. Some brought up that embryos are discarded all the time and did not consider embryo destruction in itself to be problematic. Embryos are by nature not used and destroyed all the time, and do not need to be protected for their own sake. One person said it is absurd to consider the embryo as human life with human rights. In contrary, the embryo was also seen as something intrinsically special that cannot be likened to a commodity and just thrown away. The potentiality of the human embryo was suggested to entitle the embryo a certain value that justifies questioning whether embryos are to be used for medical treatments or not, from an ethical perspective.

Moral positions concerning the use of hESC for medical treatment

There was a diversity in participants' moral positions to using embryos for therapy production. It was perceived as a complex and difficult issue that some had never thought of and triggered thoughts and feelings. One person asked herself how much we should inflict on nature. Some had no firm opinion while others were clear on what they thought. More knowledge of the effect of the treatment was important for some to decide what to think. Some thought it should be up to the experts, researchers (with no interest of profit) or legislators to decide whether the embryos should be used for medical purposes or not.

There were negative reactions after learning of the treatment. Some found it initially scary or became upset but these reactions passed away when they realized that cryopreserved embryos, and not fetuses, are used. Others described cautiously negative initial attitudes. There were worries on how the embryos are to be used and handled. One person described it felt wrong destroying an embryo that could have become a human being. Some assigned their negative attitude to it being a new treatment, not having more information about the treatment or always becoming reserved when it comes to new treatments. Not understanding why embryos need to be used made one participant suspicious.

so my first [thought] was that I will not say it was all negative but it was in the negative direction, this feels a bit tricky, what are they going to do with it, what are they after? I don't understand.

(Participant 13)

However, the participants were overall positive to the use of hESC for treatment of PD. They found the treatment interesting and exciting and thought it should be used if it could be beneficial and help others. Using surplus embryos for medicinal production was seen as something positive, "natural" or heartwarming, as it increases the utility, compared to discarding them. Also if iPS-cells would be available for treatment. Someone expressed that it was simple and intuitively easy to understand the potential of hESC. A previous receiver of transplants said it would be presumptuous of him not to accept this treatment based on his medical history. Using hESC was described to be unproblematic. One person explained that no one's integrity is threatened. Another said it was unproblematic to use embryos to repair or reduce damage, but not to improve the human being.

In this case, a person with Parkinson's has lost something existing, can you replace it in this way I don't see an ethical problem with it at all...

...I find it harder to accept that you in some way improve nature, but replacing what has been lost is not problematic to me at all.

(Participant 14)

The participants were positive to receiving treatment with cells coming from embryos themselves, some said they would accept treatment if it was offered to them. They saw the treatment as a potential help to themselves in the future. One participant said he would donate any embryos he had for medical treatment, if he would be able to.

Some thought the effects of hESC and iPS-cells should determine which of the treatments to use. The treatment that is the best should be produced. Meanwhile, some thought only iPS-cells should be used if they are available. They were preferred for avoiding the ethical issues surrounding hESC as cells from the own body could be used, and for iPS-cells being more easily available. Others preferred the use of hESC over iPS-cells. One person said it is preferable to use embryos instead of skin cells from an ethical point of view, as someone is hurt when sampling skin cells. Embryos were perceived as more appropriate

based on how they are to be used; the cells have never been specialized, they are not as old, and were believed to have a better effect than iPS-cells.

Interests related to the use of hESC for medical treatment

The participants identified several interests in the matter of using human embryos for producing medicinal therapies. They balanced interests that they identified against each other during the interviews. Their interests not only concerned them as patients but also brought up interests of others.

Interests relating to themselves as patients

The participants described an interest in having a treatment that did not limit an active everyday life, increased their health and gave them a better life with higher quality of life. An easy everyday life was desirable, without any tubes or cords attached to them and not having to take multiple doses of medicines (a) every day. Some described that learning of this therapy gave them hope of a better and longer life for themselves and/or for other patients. Participants hoped for the treatment to be used early on and slowing down the progression of the disease but they also saw it as a potential cure for PD. They hoped undergoing treatment would prolong life and reduce pain, suffering and other PD symptoms. Some were interested in increasing their functions, e.g., cognitive functions, communication abilities, mobility, help relatives and wanted to be more independent in their everyday life. One participant described how he wished he did not have to wake up his wife every night to help him get to the bathroom. Another participant wished for persons with PD to be able to return to normal again. Development of new treatment alternatives and the potential benefit for patients and relatives were used to justify the use of hESC.

The participants expressed a need for having new medical treatments against PD available. Some described that the medicines they have tested so far had no or insufficient effect. The efficacy of the treatment was described as important and there were worries that these treatments would not be efficacious enough.

Patient safety was important to the participants and they worried for side-effects of the treatment. Injecting substances into the brain was perceived as something risky. Some were solely worried about having to undergo a brain surgery, others were concerned about the substance and its short and long-term side-effects.

...what happens in the body [and] what happens in the long run in the next generation, is it something you carry with you... everyone who has Parkinson's is not 78 but there are some that get Parkinson's very early on.

If they then have children what does ... this treatment do with the next generation.

(Participant 13)

Participants worried about cell rejection, becoming ill, that the cells would be put in the wrong place or that they would lose functions such as limiting the ability to go biking or swimming.

It was important for them as patients to be met by respect, get individualized treatment and to decide their treatment together with their doctor. They wanted to be properly informed about the treatment alternatives beforehand and were interested in learning what the treatments consist of and how they are manufactured. This information would help them decide whether they would accept treatment or not. However, some participants did not find it important where the embryos came from. As patients, they were not only interested in receiving proper information about available treatment alternatives but also about research and medical advances being made within the area. This new knowledge gave them hope, not only for themselves but also for the sake of their children and future generations.

Patients' interests related to the donors

It was important for the participants that the donating woman or couple are donating embryos voluntarily. They should be able to choose if and for what purpose they want to donate and they need to give their consent. However, one person thought it was not necessary to have the couple's consent as long as it is clear that the couple is no longer in need of them. Some described it as being important that the couple get to decide what to do with their embryos without coercion and that they and their decision should be respected. The embryos were described as theirs and they should therefore be in control over them.

Some feared that women or couples will be used or exploited in the process. It was speculated that an increased embryo demand possibly would lead to a black market where embryos are traded. One person feared that an increased demand possibly could lead to pregnancies being imposed and ended against women's will in some parts of the world. There were also concerns that being able to sell embryos and get financial compensation would give couples incentives to donate embryos against their own will. Already poor and vulnerable groups were seen as being at risk of being exploited. There were disagreements when it comes to economic compensation of the donors. A "thank you" was suggested to be compensation enough while others thought it is reasonable to compensate the couple economically. However, it was seen as difficult to suggest reasonable level of economic compensation for the couple. Participants thought donors deserved to be respected throughout the process and well taken care of. They deserve to be shown appreciation and gratitude. By only allowing donation of surplus embryos from fertility treatments one would be more confident that the primary purpose of creating the embryos were to achieve a child and not to earn money.

Patients' interests related to the society

Participants acknowledged that there are various attitudes in the society regarding using embryos for medicine development. It was seen as desirable to have a joint view on this matter in the society, not having it constitutes a problem. Discussing it openly was important and efforts should be made to reach consensus, at least most people should find it acceptable. Embryo destruction was expected to upset

people considering the embryo to be life or life in being. There was an understanding of the different attitudes in the society and any resistance towards using embryos for this purpose. Public debates and headlines in the newspapers were foreseen. Some expected negative attitudes based on how e.g., abortion had been debated in some countries. They expected people to have different views for personal, ethical and religious reasons, and that some would refuse to handle the embryos for reasons of conscience. Different opinions were suggested to be met by respect.

Before deciding upon this matter, it was expressed that the question deserves careful considerations and an investigation of people's attitudes and feelings in relation to making treatment available. Legislation was suggested to be written with present and future, long-term consequences taken into account. E.g., what will happen to embryos that are donated but not used? Another pointed out that with medical advances being made continuously, any changes in the legislation might unintentionally allow us to do things in the future that one is not capable of doing, nor aware of, today. Consistency in the legislation on what you can use embryos for was considered important.

Some participants described a lack of trust in the process of producing medicines. There were worries regarding researchers and pharmaceutical companies not having an ethical compass and that they would not be handling the embryos in an ethical manner. Some thought that the embryos should be handled carefully and with respect. However, it was also expressed that they did not need to be treated in any special way. There were concerns that the pharmaceutical companies could withhold treatment from patients to increase the demand and the prices. It was stated that they had higher trust in public organizations and preferred them to be responsible for medicinal production. Information and transparency towards the general public about how treatment is developed, its pros and cons, explaining why some embryos are used and others not, was important for participants. Supervision of where the embryos come from, how the embryos are treated and being used was seen as necessary to ensure trust in the process.

Profiting on treatments developed using cells from embryos was unproblematic for some whilst others considered it to be problematic or "wrong". Some did not see it as a problem as long as no one is fooled. The industry's top priority should be patients' health, benefit the general public and make the treatment available for patients, not to profit from them or their illness. They were afraid that money could steer the direction of medical development. Some saw profiting as a problem when it restricts availability for patients, or when it comes from publicly financed research. Low costs for the patients were desired. Some saw it as more problematic to earn money on cells coming from an embryo, compared to other medicines, while others did not make any difference to them. It was important that patients' health always is higher prioritized than profit-making of the industry. Some participants preferred non-profit making organizations to produce the therapy but it was also seen as an unrealistic scenario.

Public health and having healthy citizens were valuable points for participants. There were also concerns that treatment with cells from embryos would increase the societal and global injustice. Participants wondered which patients the treatment would be available to. Medical care was seen as a human right

and participants wished for it to be available for all patients. It was believed that the pharmaceutical industry's involvement and high prices of the therapy would limit the availability for patients in need of it. Patients with the greatest needs might not even receive treatment in some parts of the world. In other parts, the prices were believed to be too high and lead to only people with the greatest needs or wealth being able to use it. Participants requested a fair prioritization between patients. Some suggested that the ones with the most severe condition should be prioritized because they have a greater need, whilst others suggested that younger patients should be prioritized because they are easier to help and still contribute to the society by working.

Patients described how it is important for the society with scientific and medical advances being made. It was seen as a possibility for co-operations over national borders. They found it important to find additional treatments and a cure for PD, for the sake of coming generations. The national economy and reducing treatment costs were seen as important and should influence whether to use hESC or iPS-cells. Using both hESC and iPS-cells in therapy development was by others seen as positive, motivating it being unnecessary to limit our options early on not knowing their full potential. Some saw the potential economic benefit to the society by using cells from embryos in treatment of PD. The treatment was seen as a possibility to reduce health care costs and increase working ability among patients.

Discussion

As described in the background there are different kinds of moral concerns among ethicists, lawyers and policy makers related to the use of human embryos for non-reproductive purposes. Regarding purposes related to medical treatment it is of special interest to explore the attitudes of patients waiting for safe and effective treatment. They are directly concerned stake holders in the sense that policy making and legislation may directly affect the possibility for improved treatment. Patients need to be informed about and consent to any treatment proposed to them by their treating doctor. The information needs to be sensitive to the special needs and concerns of the patient. In a field where there is an ongoing moral discussion in society, such as in using hESC for ATMP, a better understanding of patients' attitudes is therefore of particular relevance. It can be of help for clinicians who are expected to provide meaningful information, but also for policy makers and legislators. It may also guide the thinking and planning for other areas of cell therapy, a rapidly growing field of medical science. This is the first study that explore patients' views on using hESC for medical treatment. It reveals disclosed factual beliefs and moral concerns related to the human embryo, moral positions concerning the use of hESC for medical treatment, and interests related to the use of hESC for medical treatment. The participants had a positive or ambivalent attitude to the use of hESC in treatment of PD. Interests relating to themselves as patients, to the donors and to the society were identified and were important for the patients to take into account.

Generally speaking, patients did not consider the human embryo to constitute human life, but it was also seen as something special. The participants accepted hESC to be used in treatment although some were hesitant. It is reasonable to believe that their moral positions are consequences of their views on superfluous human embryos as not representing human life in need of protection. Profiting from

developing treatments using hESC was seen as reasonable by some while others found it problematic. There were concerns that the industry prioritizes profit over patients' well-being. Transparency is important for the trust in the industry and researchers and public debates respecting all opinions were important to the participants.

There is no previous research studying patients' views on using hESC for medical treatment but if you compare the results to previous research performed on couples, differences are found. Previous studies report individuals ascribing human embryos the same dignity and rights as humans [2, 7]. This was not found within our data collection. However, some time has passed since the previous research was performed and it was conducted within other study populations. It is expected for patients, as potentially being the ones that benefit from the treatment, to be more positive to it compared to other groups. They have experienced living with the disease and experience insufficient effects and lack of treatment. In addition, this research was performed in Sweden, one of the first European countries to enable stem cell research [19]. Previous research has indicated Swedes as having positive attitudes to the use of superfluous embryos for non-reproductive purposes. Bjuresten and Hovatta showed that more than 9 out of 10 couples approached chose to donate their surplus embryos to stem cell research [12]. Thus, the results indicate that Swedish patients with PD would accept treatment with hESC.

The results are to be interpreted with caution. It is likely that our results do not present the full picture. It cannot be excluded that some views have not been captured due to the low participation rate. The absence of foreign-borne and the high percentage of highly educated participants support that theory. It may also be the case that mostly individuals with already strong convictions decided to participate, therefore providing a full picture on the various concerns and interests. There is also a need for more research to study current views and attitudes of patients and other relevant groups as IVF-couples and the general public, as values and moral positions can change over time and with medical advances being made.

Conclusion

Patients accept the use of hESC for medical treatment as the embryo is not seen as constituting human life. However, there is some worry that the industry does not always prioritize the patient over profit and transparency is therefore seen as important. Because science, medical advances and healthcare depend on the trust they get from the society and ultimately affect the patients, it is important to take patients' views seriously and into account when deciding on how human embryos are allowed to be used.

List Of Abbreviations

hESC - Human Embryonic Stem Cells

IVF - In Vitro Fertilization

ATMP Advanced Therapy Medicinal Product - product on the market for treatment of human disorders

ATIMP Advance Therapy Investigational Medicinal Product - research phase of development prior to market permit has been obtained

iPS-cells - induced pluripotent stem cells

PD - Parkinson's disease

Declarations

Ethics approval and consent to participate

Approval was obtained from the Swedish Ethical Review Authority for conducting human interviews, before the data collection started (Dnr 2019-06539). All participants provided written informed consent to participate in the study, including for collecting background variables, and being interviewed and recorded. Data were presented in such way that no individual can be identified. All the methods were carried out in accordance with the Helsinki Declaration and relevant national and international guidelines and regulations.

Consent for publication

Not applicable.

Availability of data and materials

The datasets generated and/or analyzed during the current study are not publicly available since it contains sensitive information, but are available from the corresponding author on reasonable request.

Competing interests

HW has received compensation for education activities from pharmaceutical companies (Bristol Meyer Squibb, Abbott, Abbvie) and perform clinical studies with Herantis Pharma Y/O, Renishaw Ltd, and serve as advisor to Novo Nordisk A/S on the use of pluripotent stem cell for the clinical use in humans.

Other authors declare no competing interests related to work with the study.

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Authors contributions

MH and JD designed the study and the interview guide with substantial input from DN and HW. The interviews were transcribed verbatim and analyzed by three of the authors (JD, JVJ, EJ). JD, MH wrote a draft of the manuscript and all authors contributed with review for substantial intellectual content.

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