

“Being Guided”:

What Oncofertility Patients’ Decisions Can Teach Us About the Efficacy of Autonomy, Agency, and Decision-Making Theory in the Contemporary Critical Encounter

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Abstract

Recent research on patient decision-making reveals a disconnect between theories of autonomy, agency, and decision-making and their practice in contemporary clinical encounters. This study examines these concepts in the context of female patients making oncofertility decisions in the United Kingdom in light of the phenomenon of “being guided.” Patients experience being guided as a way to cope with, understand, and defer difficult treatment decisions. Previous discussions condemn guided decision-making, but this research suggests that patients make an informed, autonomous decision to be guided by doctors. Thus, bioethicists must consider the multifaceted ways that patients enact their autonomy in medical encounters.

Keywords: sociological bioethics, being guided, patient decision-making, autonomy and agency, empirical ethics

1. Introduction

Sociologists have long questioned the efficacy and accuracy of theories of autonomy, agency, and decision-making in the contemporary clinical encounter (Anspach 1993; Charles et al. 1997, 1999; Hedgecoe 2004; Potter and McKinlay 2005; McMullen 2012). Recent empirical research on decision-making in the clinic has shown a disconnection between what happens in theory and what happens in practice. In order to examine these theories in a particular

context, the research reported here examines how the concepts of autonomy, agency, and decision-making are understood within the context of female patients making oncofertility decisions in the United Kingdom. This article explores the phenomenon of “being guided” that was discovered in these data. To do this, it examines the different ways that interviewees experienced being guided: as a coping mechanism, as part of the existing medical treatment pathway, and by “being railroaded.” Finally, discussing the relationship of being guided to existing theories of autonomy, agency, and patient decision-making, this article provides a critique of the overreliance on the principlist account of autonomy in current policy and practice.

2. Background

The contemporary medical encounter is shaped by the tension between our right to make a personal choice and what Annandale calls “the moral responsibility to actually make these choices” within the “constraints that surround decision-making for both patients and health-care providers” (Annandale 1998, 252). In other words, although every patient has the right to autonomy, operationalising that right through hard and decisive decision-making is not without difficulty. Contemporary society places a high value on the “authority of the self amid competing ideas about how illness should be understood and treated” (Annandale 1998, 252), and as a result patients, as individual decision-makers, bear the ultimate responsibility for their care.

The emphasis on supporting the authority of patient choice reflects the importance of the bioethical concept of patient autonomy in medical practice; patient autonomy lies at the very heart of best practice in medicine, and legal requirements for informed consent before treatment highlight the seriousness with which patients, practitioners, and lawmakers view autonomy. Traditionally, bioethical concepts of autonomy in medicine have been largely

based on Tom Beauchamp and James Childress's concept of respect for autonomy, which fuses "the Kantian concept of respect for persons with [J. S.] Mill's quite different notion of liberty; that is, persons' choice of action should not be obstructed unless those actions infringe upon the liberty of others" (Jonsen 1998, 335; see also Mappes and Degrazia 2006; Jonsen 1998; Beauchamp and Childress 2009). As Beauchamp and Childress (2009) are concerned with the role of choice in healthcare, their principle of autonomy has focused more specifically on "autonomous *choice*" (100). Autonomous choice occurs when individuals are free from constraint, exercise self-governance, and have sufficient understanding of the information with which they are presented (Beauchamp and Childress 2009). Decisions that satisfy the above criteria are considered "autonomous," and by extension morally "right," because they respect the patient's right to make their own choices.

Whereas bioethicists have tried to prescribe the way that patients *should* make decisions, sociologists have concerned themselves with capturing how decisions are made *within* patients' specific social contexts. Asking patients for treatment preferences is becoming one of "the most basic forms of patient involvement in medical care" (Zikmund-Fisher et al. 2012, 198). The "best choice" for patients is no longer just about the best medical treatment for their illness but should also be grounded in "the preferences, values, and goals of the patient" (Zikmund-Fisher et al. 2012, 198). This constitutes a move away from older, paternalistic models of medical decision-making towards a more inclusive understanding of the process of decision-making itself. Shared decision-making, in particular the version of it described by Cathy Charles et al., (1997, 1999), has been the focus of much research, perhaps because it embodies a patient-centred care ethos that many medical systems espouse.

Unfortunately, in practice "researchers widely acknowledge that an actual decision-making process rarely fits any of these idealised models," and empirical studies have shown that "shared decision-making does not often occur in practice" (McMullen 2012, 238).

Instead, empirical work indicates that more paternalistic models remain at work in clinical practice (Towle et al. 2006; McMullen 2012). Although healthcare professionals may wholeheartedly believe in the rhetoric of patient autonomy, consent, and shared decision-making, they appear unaware that they are not actually putting those beliefs into practice (McMullen 2012). Patient experience, thus, remains at odds with the so-called patient-centred care approach supposedly adopted by contemporary Western medicine and boldly disregards theoretical accounts of autonomy that are supposedly so highly valued in bioethics and sociology.

One approach to examining patient autonomy and decision-making that might help resolve the tension between theory and practice is empirical ethics (Haimes 2002), particularly the concept of sociological bioethics (Paton 2017, 2018). Sociological bioethics is part of a growing trend of examining bioethical theories in practice through the sociological lens (Paton 2017, 2018; Haimes 2002; Hedgecoe 2004; Scully 2010; Frith 2012; Riesch et al. 2018). Using sociological methods, methodology, and theory makes it possible to explore how patient autonomy manifests in practice and to examine the extent to which the operationalisation of patient autonomy theory occurs in actual patient decision-making in real-life medical encounters.

In order to better understand how ongoing practices of patient decision-making can inform existing theories, I interviewed premenopausal women diagnosed with cancer and asked them to reflect on how they made decisions about their cancer treatment, their future fertility, and their fertility preservation. These women were patients in an emerging field in medicine, oncofertility, which brings together oncology with infertility techniques to help preserve fertility from the damage that oncology treatments can cause. In the last ten years, oncofertility treatment choices for women have evolved rapidly, beginning with embryo freezing for those with partners or sperm donors and now including more singular forms of

fertility preservation, such as the development of successful egg freezing (Jadoul et al. 2010). Current research into ovary freezing (Wallace and Barr 2010), and experimental work on reproductive technology more generally, has changed the landscape of oncofertility options dramatically in a short period of time. The field of oncofertility has also changed, owing to advances in cancer treatment and survival rates for women increasing to 50 percent in the last forty years (Cancer Research UK 2014). As cancer survivorship grows, life after cancer has become an important consideration for patients, leading to an increasingly complex relationship between decisions around cancer treatment options and fertility preservation options (Quinn et al. 2007).

A different account of making decisions, something the women called “being guided,” emerged from these interviews with oncofertility patients. Unlike idealised accounts of patient decision-making that look to patients to strongly and actively assert their autonomy and make definitive decisions, patients described “being guided” as a more passive-assent approach to making decisions; a passive approach that the women all identified as a *choice* they had *made* and were willingly taking part in. The participants’ different experiences of making decisions through this process of “being guided” highlight the ways that patients make decisions that differ from idealised, theoretical conceptions of patient decision-making in the medical encounter that must influence practice around decision-making and consent.

3. Methods

To examine the experiences of oncofertility patients through the sociobioethical lens, one-to-one interviews were conducted with premenopausal (eighteen- to fifty-year-olds) cancer patients with a focus on their lived experiences of making oncology and fertility decisions (Brewer 2000; Mason 2002; Silverman 2004). The research received ethical approval from Newcastle University and The Newcastle Hospitals NHS Foundation Trust. Regional and

national support groups were identified through the website databases from Macmillan (2019) and Cancer Research UK (2014). To recruit participants, I initially contacted support groups in the Northeast of England and asked if I could attend a meeting to present on this study. After receiving an invitation to attend a meeting, I would present to their members about the project and provide informational pamphlets about the study to any interested participants. Those that wanted to participate signed consent forms, and I organized an interview, either face-to-face or over the phone, between myself and each participant. I conducted semi-structured interviews with eleven patients. No particular cancer diagnosis, stage, or prognosis was targeted (see Tables 1 and 2). Contacts in the groups from the Northeast led to groups further south wishing to take part as well, and interviewees were predominantly from the Northeast and Southeast of England. While it would be tempting to offer some discussion on the demographics of the interviewees, no particular socioeconomic or cultural group was sufficiently represented to draw any significant conclusions with regards to demographics. I recorded interviews and obtained consent from all interviewees a second time before the interview began. Interviews ranged in length from forty-five minutes to two hours and were fully transcribed, anonymised, and de-identified for the analysis phase.

Age of Participant (Years)	Number of Participants
18–32	4
33–38	1
39–44	2
45–50	4

Table 1: Age of patient participants at the time of diagnosis

Cancer Type	Number of Participants
Gynaecological	3
Breast	6
Brain	2

Table 2: Cancer diagnosis of participants

Data from these interviews were analysed using a grounded theory-inspired approach (Brewer 2000) combined with thematic analysis (Attride-Stirling 2001). Social, sociological,

and bioethical theories were also used as sensitising concepts for analysis, with an emphasis on theories of autonomy, agency, and patient decision-making. In particular, traditional autonomy (Beauchamp and Childress 2009), relational autonomy (Mackenzie and Stoljar 2000), and contemporary accounts of patient decision-making (Charles et al. 1997; McMullen 2012; Zikmund-Fisher et al. 2012) were used to examine the data across both the bioethical and sociological fields of analysis. Analysis of the empirical data, thus, reflects on the accuracy and relevance of current theories of bioethical autonomy that inform policy and practice in the contemporary clinical context.

Following Kristi Malterud et al. (2016), this study aimed to achieve information power. As Malterud et al. (2016) argue, “Information power indicates that the more information the sample holds, relevant for the actual study, the lower amount of participants is needed” (1). Following the information power guidelines, eleven interviews was considered sufficient for the findings to achieve information power as the study aims were narrow, to use Malterud et al.’s (2016) terminology, the required sample required was highly specific (premenopausal women who made fertility preservation decisions in the North and Southeast regions), the interview data was in-depth and of high quality, and the project had a robust analysis strategy that employed many established theories (Malterud et al. 2016). Additionally, the “appraisal of information power” was repeated throughout the research, whereby, after the preliminary first interviews, a review of the data and consideration for possible relevant theories was made to ensure that the data was appropriate to the research question (Malterud et al. 2016, 1757). Appraisal of information power allows “initial analytic ideas” to emerge from the data (Malterud et al. 2016, 1757), such that the concept of information power as a whole sat comfortably alongside the similar grounded theory process of constant comparison, which I also engaged in during data analysis (Brewer 2000; Charmaz 2006).

4. “Being guided”

In interviews the women often described “being guided” by their doctors, and they spoke about “agreeing” with their doctors’ decisions or “deciding” to be guided by their doctors. The phrase itself comes “in vivo” from one of the participants, Mary, who when asked if she felt *she* was making decisions throughout her treatment responded, “I felt like I was *being guided*” (emphasis added). Participants experienced being guided in three significant and overlapping ways. First, many allowed themselves to be guided as a coping mechanism that helped them deal with a lack of clinical knowledge, uncertainty, and the emotions of being diagnosed with cancer. Second, participants described being guided along an existing recommended treatment pathway that informed the decisions they had already made. Third, when participants felt they were given little or no choice in their care, the phenomenon of being guided was described in more negative terms, for example as “being railroaded.”

a. Being guided as a coping mechanism

Participants allowed themselves to be guided by their healthcare professionals’ suggestions and decisions as a coping mechanism in two distinct ways. First, interviewees depended on being guided as a way to cope with the emotional distress caused by their diagnoses. To avoid some of this distress, they chose to abdicate decisional responsibility to their doctors. Second, interviewees let themselves be guided as a way to cope with their lack of clinical knowledge, and those that trusted their healthcare professionals and their expertise solicited recommendations for treatment options to help them make decisions they perceived as difficult to cope with due to distress or complexity of choice.

Heather is a good example of someone who chose to delegate much of her decisional responsibility to her doctors as a way of coping with the emotional stress of having cancer.

She explains:

I didn't care what they did. I just wanted someone to say at the end of the hospital visit "Everything is fine" So my way of coping was I shut off. I didn't want to know. And I remember saying to my husband "Just don't ask nothing, we're just doing what we got to do."

Although it may appear that Heather is too distressed to make any decisions about her treatment, she was, in fact, making a very important decision that achieved two important goals for her: by abdicating her decisional responsibility to her doctor she could cope with the stress of being diagnosed with cancer, and, at the same time, she still took steps towards being cancer free. Heather "wanted to be better," and the best way for her to achieve being better was to "shut off" and not know what was happening. Heather actively decided this when she told her husband not to ask questions, making the decision that "we're just doing what we got to do." In this way Heather used her choice to be guided as a way to safeguard her emotional wellbeing.

Monica was equally upfront about her use of being guided as an emotional coping mechanism: "Because I don't think I asked any [questions] first time round. I just went along with it I felt like decisions were made for me, but I was quite happy with that." Again, at face value, Monica appears to have surrendered her ability to make decisions, however her assertion that she was "happy" to go along with the doctors' decisions indicates that she made an initial decision to abdicate decisional responsibility that contributed positively to her experience of coping with cancer.

In contrast to Monica and Heather, some of the interviewees used being guided as a coping mechanism for their lack of clinical knowledge by asking their doctors' opinions for guidance with decisions they perceived as difficult. A number of the women chose to be

guided by the opinions of their doctors when it came to more difficult decisions that they had to make about treatment and aftercare. For example, Anne asked her doctor outright what she would do in her position to help guide her in making a decision about which treatment to choose: “I sort of asked the question, ‘If it was you sat here what would you do, if you were me what would you do?’ And she said “... I would get it out.” Another interviewee, Amy, also turned to the opinion of her doctor when making decisions about her chemotherapy care: “she said ‘... you really can’t afford to wait that long.’ She made me aware that the option [for fertility preservation] was there but she also made it clear that she didn’t recommend that I wait that long.” For Diane, guidance from her doctors helped her make difficult decisions for her aftercare: “I definitely needed help. Definitely needed help, guidance. Not guidance in the sense of them saying—I just knew that they had seen it all before so I just needed case studies if you like, examples of other women. ... It does put it in context for you.” Robyn was the most explicit about how she employed the choice to be guided as a mechanism for coping with the difficult clinical world in which she had to make decisions:

I was certainly being led by a good team and yes I had certain elements of choices, but I have to be guided ultimately by an excellent consultant who knows his job inside out. I don’t know his job, but he does, and I’ve got to just lay down and give him my life really ... and yes I had choices and yes I had to be led and in some respects you need to be led because your brain is quite full of other things.

In all four examples the women were also trying to discover the context around their disease by asking for suggestions from their doctors. For example, Anne did so overtly, asking “if you were me what would you do,” while Amy subtly listened to the recommendations from her doctor that she “can’t afford to wait that long.” By soliciting their doctors’ suggestions on

what decision the doctor would take, interviewees choose to be guided towards what they felt was an expert understanding of the context within which their own decisions had to be made.

b. Being guided by the existing medical treatment pathway

All the participants felt there was an aspect of being guided down an already existing path due to the treatment pathways that clinicians follow. Healthcare professionals, as much as their patients, are constrained by the pathways ascribed to their patient's treatment. While options do remain available, the treatment pathways are frameworks within which only limited options are possible. In this study, interviewees often made reference to their treatment pathways and the restricting effect that these pathways had on their choice to be guided.¹

For those interviewees who were diagnosed with advanced cancer the link between being guided and the treatment pathway stood out prominently. Amy's experience illustrates how with aggressive cancer like her advanced breast cancer, the treatment pathways can often guide the patient towards only one available option, which then frames all other choices that come afterwards:

... an appointment was made for me to see her and ... she had basically said you're going to need chemotherapy, you're going to need it soon ... and that it really was a case of getting the chemotherapy done first So it was clear that it was big and it was bad and you know they were able to say you need to start this treatment. (emphasis added)

The lack of options is apparent in Amy's use of language, emphasised above: chemotherapy had to come first if she was to have a chance at surviving. When recounting her diagnosis and treatment in her interview, it was only after chemotherapy that Amy started to discuss the options she felt were available and the subsequent choices that she made; every choice before

that was guided by the treatment pathway, which prescribed chemotherapy as a first course of action for survival.

Angela's experience is also a good example of this phenomenon, as the severity of her cancer meant that the best available treatment for survival was a mastectomy. She was, however, reluctant to accept the mastectomy as her only treatment option. Like Amy, Angela felt that the treatment pathway dictated the choices available and the guidance offered by her doctors:

[sighs] Choices, now I was sort of basically told this is what we need to do to cure you. ... I did contemplate not having the breast removed, and saying no, that's it. I'd have the chemo but I would not have the breast off, I was so determined. ... There wasn't a point where it was "have this or this and be cured," it was "do this and be cured" or "not do this and not be cured" So I didn't have any choices of treatment, just this was the one choice

In Angela's opinion she had a choice to make between being guided by her doctors and the viable treatment pathway or not having the surgery. Angela chose to be guided by her doctors and follow the suggested treatment, which was the only treatment available to her in order to "be cured." However, the "or else" of death lingers in her account, unsaid, but understood.

c. Being railroaded

Some of the participants described situations when being guided by their doctors became what I describe as "being railroaded." Just as other interviewees described being guided, Kathleen suggested the term "railroaded" in vivo during her interview. For many of the participants, the experience of being railroaded was closely linked to their relationship with their doctors and the trust or distrust that developed from that relationship. The relationship

between patient and doctor was an integral aspect of whether the interviewees felt they were guided or railroaded by their doctors, which in turn changed how interviewees perceived whether they did or did not make decisions. While descriptions of being railroaded were infrequent in the data, it is an important negative sub-type, or even possible negative consequence, of being guided that warrants discussion. Examining the phenomena of being railroaded helps to highlight how delicate the balance is between respecting/supporting patient autonomy and decision-making, and the doctor simply doing what they feel is medically best without regard for the patient's own values and beliefs.

Kathleen, in particular, felt that she was "railroaded" into her treatment. Kathleen was diagnosed with vulval cancer while pregnant and advised by her doctor to terminate the pregnancy, undergo a radical vulvectomy, and be sterilised. She explains:

And I kind of then started getting quite angry and thinking that I wasn't kind of given a choice, *I was railroaded into this [treatment]*. I didn't have a second opinion. I assumed I was being sent the best, but really should have asked for a second opinion. I think it was all the panic with time and pregnancy I just wanted to be alright. And again that goes down to ignorance, I didn't know enough. And yes my consultant drew a diagram, but did I know enough about my own body? Did I see photos, no? Would I have made the same decision if I'd seen a bit more? How I was going to be left? I really don't know. It's alright sitting at this age, in hindsight, knowing what you know. But at the time, I mean ignorance. Would I have made the same decision? I don't know. I don't know if I would have agreed. I mean sterilised? I don't know if it was necessary. (emphasis added)

Kathleen felt she was railroaded into making decisions for two reasons. First, she felt she was

not given the time or opportunity to consider the treatment options available to her. Second, the available options were restricted by her doctor, who, Kathleen later found out, only presented the treatment options he had already chosen for her without regard for her own opinion on the outcomes. Initially Kathleen allowed herself to be guided, but that was based on a level of trust that she eventually lost when she discovered, through a second physician, there were many viable treatment options available that her first doctor had ignored due to malpractice on his part. This discovery shifted her experience from being guided to being railroaded. Kathleen's reaction to being railroaded is indicative of the link between being guided and decision-making, as the anger that Kathleen expressed was about her lack of treatment choices as a result of misguidance on the part of her doctors. Given the enormity of the decision she was making (whether to agree to a pregnancy termination, radical vulvectomy, and sterilisation) within the same week of her cancer diagnosis, she felt she should have been given better guidance on the choices to consider.

While Kathleen was a very specific case, other interviewees felt that being guided could briefly become being railroaded. This change was due to the way that doctors communicated options and suggestions, which left little room for discussion. Being guided was experienced as being railroaded when the interviewees perceived that the doctor stopped communicating and working *with* them and instead were speaking *to* them and working *on* them. For example, Anne felt that being guided became being railroaded when her doctors started to tell her what they were going to do without asking her opinion on those choices. The shift between the two is evident in the language Anne used to describe her experience: "Because it's all about your business and 'We're going to do this. We're going to do that. You've got to come back, and we're going to look at you.' There's not any, 'Well, how do you feel about that?' Or, you know, 'Is that OK with you?'" The "we're going to" imperative phrasing by her doctors is contrasted, in her account, with the interrogative questioning she

would have preferred to ensure she was “OK” with what she felt were her doctors’ suggestions.

Perhaps the most interesting example is that of Monica, who had breast cancer twice and experienced being guided both positively and negatively. Monica was “happy” to be guided the first time she had cancer. However, the second time around she was not comfortable with being guided, and she experience her doctors’ attempts to guide as railroading:

But this time round because I was more clued up, I wanted a lot more say in what happened Whereas the first time around I probably would have just gone along with whatever it is that they told me, whereas this time I think, “No, I don’t have to do that” I just think it’s age this time. I think last time ... I just went along with whatever the professionals told me to do. They knew better. They knew what they were doing and I just trusted them. Whereas this time, I don’t have that trust. I feel more like I should question everything.

Monica felt she had to question their suggestions as she “wanted a lot more say in what happened” with her treatment. She attributed the difference in her response to the two cancer diagnoses to trust and age: Monica knew much more about what to expect the second time around, which changed the information, communication style, and relationship that she needed to make decisions. Additionally, she trusted her doctors less the second time around, as she felt they often gave her poor advice, or advice that went against her first experience with cancer. As a result, she was less willing to choose to be guided during her second diagnosis.

The phenomenon of being railroaded is a significant concern for patient autonomy

and agency as it shifts the patient from being an autonomous member of her treatment team to being the passive object of interest of the team. The strong reactions participants expressed when they felt they were railroaded indicates the importance that they attach to maintaining autonomous decision-making, even in the most passive of forms. Being railroaded is an example of how autonomy is still not always respected in the relationship between patient and doctor, or within the medical encounter. Railroaded impedes patients from exercising their agency, and choosing to be guided did not mean abdicating autonomy to a well-meaning but single-minded clinician. Perhaps, as a result, interviewees who experienced being railroaded often did not have a good relationship with their doctors from that point onwards, as the switch to a railroading approach eroded the initial trust that they placed in their doctors when they chose to be guided.

5. Discussion

While participants did not view being guided as a step away from autonomy or a step towards paternalism, concepts similar to being guided have been viewed in an almost uniformly negative light. Previous research has not favourably viewed the role of doctors' recommendations in facilitating patient autonomy (Frongillo et al. 2013). The wider literature has condemned doctors' recommendations as restricting patient decision-making, arguing that recommendations can force patients onto a "conveyor belt" towards a particular treatment (Scully et al. 2007) and that patients will defer to doctors' authority over their own, instead of making autonomous choices (McMullen 2012; Frongillo et al. 2013). There is a long history of discussion of doctors' recommendations and patient assent to these recommendations that often veers towards accusations of paternalism (Emanuel and Emanuel 1992; Charles et al. 1997; Charles et al. 1999), especially with regard to "professional choice" (Morgan 2008).

The data presented here paints a different, more positive picture, indicating that patients may be doing more than just passively cooperating with the decisions that their doctors make. Instead, patients may also be actively agreeing to these decisions in a way that they view as distinct, deliberate, and autonomous. There are, I would like to argue, two important forces at work when it comes to understanding the complexity of being guided and what can be learned from this style of making decisions. The first is the continually underrated role of trust in facilitating patient autonomy. The second is the restricting effect caused by medicine's continued overreliance on the principlist account of autonomy when structuring policy that influences practices to do with facilitating patient autonomy.

a. Trust and being guided

In the data, interviewees describe their experience of being guided as strongly rooted in their relationships with their doctors and the resulting trust those relationships did or did not foster. Trust has been previously identified as important to patient decision-making as doctors are "trusted for their perceived specialist knowledge and expertise, but also for their interpersonal skills" (Nelson et al. 2012, 800). Patients are likely to rely heavily on guidance from their doctors, and they will often defer to them as perceived experts (Kim et al. 2013).

Trust also helps to distinguish being guided from "soft paternalism," whereby patients' assent to physicians' decisions takes the place of active decision-making (Emanuel and Emanuel 1992; McMullen 2012). Trust in their doctors played a key role in how interviewees experienced being guided, which, in turn, influenced their perception of making the decision to be guided, as well as how and why they made that choice. Unlike patient accounts of paternalism, interviewees did not (for the most part) experience being guided as a loss of or lack of respect for autonomy (except, significantly, when it strayed into railroading). Nor did they view it as an impediment to making decisions in the medical

setting. Instead, these interviewees experienced being guided as a process whereby they made the autonomous decision to put their trust in someone else. The important role that trust plays in facilitating a patient's enactment of their autonomy has been identified before (Paton 2017), however this importance has yet to trickle down in any significant way to policy, and some may even argue, practice. This is perhaps due to the second point I would like to make when discussing the phenomenon of being guided: the pervasive dominance of the principlist account of autonomy in medicine.

b. The principle of autonomy: Still king of the hill?

Because the concept of being guided developed in vivo from the data, the term proves difficult to find in the literature. However, other studies have identified this style of making decisions both positively and negatively, and more careful examination of them highlights why the idea of abdicating decisional responsibility or deferring decisions to doctors has been viewed in such a negative light.

In their study of clinicians' perspectives of how parents made decisions to terminate a pregnancy following the diagnosis of a severe congenital anomaly, Lotto et al. (2017) identified clear expectations in clinicians that parents make decisions along a set of clear (to the physicians) criteria that culminated in an active and decisive decision made by the parents. Clinicians wanted parents to engage in what they called "rational" decision-making, whereby they felt that parents actively engaged in behaviours they knew on paper to facilitate informed, autonomous decision-making. Namely "weighing up relevant information, deliberating over the future impact of the decision, balancing risk," and most importantly clinicians felt this had to result in the "implementing" of a decision by the parent (Lotto et al., 2017, 4). Lotto et al.'s study highlights how clinicians can have very clear expectations of decisional responsibilities that parents should meet. But where do these expectations arise

from? I argue that the principlist account of ethics in medicine, referring to Beauchamp and Childress's four principles of bioethics, has ingrained a particular expectation of what autonomy *should* look like in practice. But, as Lotto et al.'s study and the phenomenon of being guided have shown, patients do not make decisions that cleave to the theoretical categories of decision-making that currently inform policy or practice around patient autonomy.

Aasim Padela et al. (2015), in their study of patient autonomy in western and eastern contexts, similarly argue that the "four principles based biomedical model remains the dominant ethical framework wherever modern medicine is practiced" (99). Such is its prominence that the principle for the respect for autonomy is prevalent in every aspect of medicine: from training all the way through to formalised ethics consultation processes (Padela et al., 2015, 101). Padela et al., argue that respect for autonomy has become "strongly associated with the notion that patients should be making their own decisions" (101). However, I would like to push that argument further and echo the relational autonomy critique that respect for autonomy has become synonymous within medicine with the concept of a patient who can only act autonomously if they are making active and decisive decisions.

Phenomena like that of being guided go against the grain of the principlist account of how patients should make decisions. Thus, they warrant further consideration of what they can tell us about how patients enact their autonomy and how policy and practice may be out of step with the patient experience. For example, one study describes being guided as a delegation of decision-making from patient to doctor, which was seen as "an active choice in which [patients] described feeling that their views were taken account of" instead of a return to paternalism (Nelson et al. 2012, 801). Very few participants in my research described being coerced into a decision or forced to follow the doctor's suggestion as the concept of paternalism suggests. Instead, most interviewees felt that they had actively made the decision

to be guided. Their active choice of allowing themselves to be guided was both an affirmation of their control over their medical decisions and, from a bioethical and sociological point of view, evidence that they were exercising their autonomy and agency in the medical context.

Even in the face of rigid treatment pathways, interviewees described an ownership and agency over decisions, though this was often from a limited set of options. In the literature this has been described by patients as a distinction they make between “doing something” and “doing nothing,” where “doing something” characterised the treatment choices available after the birth of a child with cleft palate (Nelson et al. 2012). Nelson et al. argue that parents did not describe making individual choices for each treatment but instead recognised a larger choice between “doing something” and “doing nothing.” In a sense, there is something similar happening when patients are guided by the existing treatment pathway: they are choosing to “do something” by following the prescribed course of treatment as recommended by their physician. Angela perhaps put it best when she said “It was this and be cured or not do this and not be cured ... this was the one choice.”

In a similar vein, Padela et al. (2015) argue that different “local moral experiences” shape how patients want to exercise their autonomy around the globe. They discuss this with regards to an east-west, developed-developing country, divide, but “local moral experience” and its situated context can also be *very* local, right down to individual people. Their specific contexts, the way that they understand and value relationships, trust, expertise, and information, governs how they will ultimately choose to enact their right to autonomous decision making. For example, the difference between an experience being perceived by interviewees as being guided versus being railroaded often came down to the positioning and preferences of the patient, alongside a divergence in clinical practice by doctors who favoured guiding or railroading styles of communication.

These personal preferences of patients point to the importance of healthcare

professionals not making assumptions about whether/how any given patient would like to be guided either. Participants emphasised the importance of healthcare professionals talking through options, including the reasons why some options may be preferable to others, even if there was a sense of inevitability in the option ultimately chosen. Lip service to informed choice by doctors who were perceived to restrict options ultimately led to a sense of being railroaded. The anger participants felt towards railroading points to the extent of patients' need to see the options for themselves (however futile) and highlights how that need is a fundamental component of respecting patient autonomy for any individual patient. It also highlights how strongly participants felt they had made an autonomous decision to be guided when they had chosen to do so.

6. Conclusion

When autonomy is understood as individual and person-centric in the way the principles are taught and conceived of in medicine, it limits "accepted" enactment of autonomy to those active and decisive forms that favour individuals in isolation; thus disregarding the way patients value the relationships around them and the influences of their social context (Padela et al. 2015; Mackenzie and Stoljar 2000). While policy remains rooted in a principlist account, it will continue to inform practices that discount how varied patients' understandings of autonomy can be, glossing over the "local moral experience" that all patients bring with them into the medical encounter (Padela et al. 2015).

Perhaps here is where relational autonomy can provide a theoretical scaffolding to patient autonomy that better reflects not just the different contexts within which patients make decisions (be they socioeconomic, cultural, etc.) but also the different ways that patients understand and enact their own autonomy. If policy on what constitutes respect for persons was based on a more relational account of who a person is, it would allow for

concepts like being guided to be considered as legitimate ways that patients act autonomously. Additionally, better recognition of the different ways that autonomy is enacted would also provide better support and protection against phenomena like being railroaded. Instead, the continued reliance on principles ignores concepts like being guided altogether, leaving all patients who make decisions outside of this accepted and expected norm in the shadows without proper support and physicians panicking about how best to support a patient who looks to them for guidance.

Despite its continued presence in patient accounts of decision-making, what is steadfastly ignored in theory, and the policy and practice that it informs, is that how patients choose to enact their autonomy is specific to them. Patients rarely use the terminology of “autonomy” or “autonomous,” any more than they make decisions in a way that manifests itself in the precise account of autonomy prescribed by the principlist account. Instead, patients use terms like being guided to represent the middle path sometimes taken between the textbook ideal of autonomy and its antithesis, being railroaded.

Being guided, and the passive style of autonomy that it represents, highlights the variable nature of patients’ approaches to making autonomous decisions. Accounts of patients who actively (and happily) choose to abdicate, defer, or passively assent to their healthcare professionals’ decisions, or simply choose “something” over “nothing,” requires further attention in the literature to better understand why patients often prefer this style of decision-making to the overtly active and decisive form of patient autonomy championed in medical policy, training, and practice.

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NOTES

1. The effect that medical protocols have on patient decision-making is also an example of how institutions can interact with and influence the agency and autonomy of individuals (Giddens, 1979, 55-58; Mackenzie and Stoljar, 2000, 22 and 223).

REFERENCES

- Annandale, Ellen. 1998. *The Sociology of Health and Medicine: A Critical Introduction*. Cambridge: Polity Press
- Anspach, Renee R. 1993. *Deciding Who Lives: Fateful Choices in the Intensive Care Nursery*. Berkeley: University of California Press
- Attride-Stirling, Jennifer. 2001. "Thematic Networks: An Analytical Tool for Qualitative Research." *Qualitative Research* 1 (3): 385-405.
- Beauchamp, Tom L., and James F. Childress. 2009. *Principles of Biomedical Ethics*. 6th edition. Oxford: Oxford University Press.
- Brewer, John D. 2000. *Ethnography*. Buckingham: Open University Press.
- Cancer Research UK. 2014. Cancer Statistics for the UK. London: Cancer Research UK. <http://www.cancerresearchuk.org/cancer-info/cancerstats/keyfacts/Allcancerscombined/>
- Charles, Cathy, Amiram Gafni, and Tim Whelan. 1997. "Shared Decision-Making in the Medical Encounter: What Does It Mean? (Or It Takes at Least Two to Tango)." *Social Science and Medicine* 44 (5): 681-92.

- Charles, Cathy, Amiram Gafni, and Tim Whelan. 1999. "Decision-Making in the Physician-Patient Encounter: Revisiting the Shared Treatment Decision-Making Model." *Social Science and Medicine* 49: 651-61
- Charmaz, Kathy. 2006. *Constructing Grounded Theory: A Practical Guide through Qualitative Analysis*. Thousand Oaks: Sage Publications.
- Childress, James F. 1990. "The Place of Autonomy in Bioethics." *The Hastings Centre Report* 20 (1): 12-17.
- Emanuel, Ezekiel J., and Linda L. Emanuel. 1992. "Four Models of the Physician-Patient Relationship." *The Journal of the American Medical Association* 267 (16): 2221-29.
- Frith, Lucy. 2012. "Symbiotic Empirical Ethics: A Practical Methodology." *Bioethics* 26 (4): 198-206.
- Frongillo, Marissa, Sandra Feibelman, Jeff Belkora, et al. 2013. "Is There Shared Decision Making When the Provider Makes a Recommendation?" *Patient Education and Counseling* 90 (1): 69-73.
- Giddens, Anthony. 1979. *Central Problems in Social Theory*. Los Angeles: University of California Press.
- Haimes, Erica. 2002. "What Can the Social Sciences Contribute to the Study of Ethics? Theoretical, Empirical and Substantive Considerations." *Bioethics* 16 (2): 89-113.
- Hedgecoe, Adam M. 2004. "Critical Bioethics: Beyond the Social Science Critique of Applied Ethics." *Bioethics* 18 (2): 120-43.
- Jadoul, Pascale, Marie-Madeleine Dolmans, and Jacques Donnez. 2010. "Fertility Preservation in Girls During Childhood: Is it Feasible, Efficient and Sage and to Whom Should it be Proposed?" *Human Reproduction Update* 16 (6): 617-30.
- Jonsen, Albert R. 1998. *The Birth of Bioethics*. New York: Oxford University Press

- Kim, Jayeon, Allison M. Deal, Ursula Balthazar, et al. 2013. "Fertility Preservation Consultation for Women with Cancer: Are We Helping Patients Make High-Quality Decisions?" *Reproductive Biomedicine Online* 27: 96-103.
- Lotto, Robyn, Lucy K., and Natalie Armstrong. 2017. "Clinicians' Perspectives of Parental Decision-Making Following Diagnosis of a Severe Congenital Anomaly: A Qualitative Study." *BMJ Open* 7. <https://doi.org/10.1136/bmjopen-2016-014716>
- Mackenzie, Catriona, and Natalie Stoljar. 2000. *Relational Autonomy: Feminist Perspectives on Autonomy, Agency and the Social Self*. New York: Oxford University Press.
- Macmillan. 2019. MacMillan Cancer Support. <https://www.macmillan.org.uk>
- Malterud, Kirsti, Volkert Dirk Siersma, and Ann Dorrit Guassora. 2016. "Sample Size in Qualitative Interview Studies: Guided by Information Power." *Qualitative Health Research* 26 (13): 1753-60.
- Mappes, Thomas A., and David Degrazia. 2006. *Biomedical Ethics*. 6th edition. New York: McGraw-Hill Higher Education.
- Mason, Jennifer. 2002. *Qualitative Researching*. 2nd edition. London: Sage Publications.
- McMullen, Linda M. 2012. "Discourses of Influence and Autonomy in Physicians' Accounts of Treatment Decision Making for Depression." *Qualitative Health Research* 22 (2): 238-49.
- Morgan, Myfanwy. 2008. "The Doctor–Patient Relationship." In *Sociology as Applied to Medicine*, ed. Graham Scambler, 55-70. London: Saunders Elsevier.
- Nelson, Pauline Anne, Ann-Louise Caress, Anne-Marie Glenny, et al. 2012. "'Doing the Right' Thing': How Parents Experience and Manage Decision-Making for Children's 'Normalising' Surgeries." *Social Science and Medicine* 74 (5): 796-804.
- Padela, Aasim I., Aisha Y. Malik, Farr Curlin, et al. 2015. "[Re]Considering Respect for Persons in a Globalising World." *Bioethics* 15 (2): 98-106.

- Paton, Alexis. 2017. "No Longer 'Handmaiden': The Role of Social and Sociological Theory in Bioethics." *IJFAB* 10 (1): 30-49.
- Potter, Sharyn J., and John B. McKinlay. 2005. "From a Relationship to Encounter: An Examination of Longitudinal and Lateral Dimensions in the Doctor-Patient Relationship." *Social Science and Medicine* 61 (2): 465-79
- Quinn, Gwendolyn P, Susan T. Vadaparampil, Clement K. Gwede, et al. 2007. "Discussion of Fertility Preservation with Newly Diagnosed Patients: Oncologists' Views." *Journal of Cancer Survivorship* 1 (2): 146-55.
- Paton, A. (2018). "It's not just about having babies': A socio-bioethical exploration of older women's experiences of making oncofertility decisions in Britain.", in Riesch, H., Emmerich, N. & Wainwright, S. (Eds). *Philosophies and Sociologies of Bioethics*. Springer.
- Scully, Jackie Leach. 2010. "From Theory to Method." In *Feminist Bioethics: At the Center, On the Margins*, eds. Jackie Leach Scully, Laurel E. Baldwin-Ragaven, and Petya Fitzpatrick, 131-38. Baltimore: Johns Hopkins University Press.
- Scully, Jackie Leach, Rouven Porz, and Christoph Rehmann-Sutter. 2007. "You Don't Make Genetic Test Decisions from One Day to the Next': Using Time to Preserve Moral Space." *Bioethics* 21 (4): 208-17.
- Silverman, David, ed. 2004. *Qualitative Research: Theory, Method and Practice*. London: Sage Publications.
- Towle, Angela, William Godolphin, Garry Grams, et al. 2006. "Putting Informed and Shared Decision Making into Practice." *Health Expectations* 9 (4): 321-32.

Wallace, W. Hamish, Alice Grove Smith, Thomas W. Kelsey, et al. 2010. "Fertility Preservation for Girls and Young Women with Cancer: What are the Remaining Challenges?" *Human Reproduction Update* 16 (6): 614-16.

Zikmund-Fisher, Brian J., Mick P. Couper, and Angela Fagerlin. 2012. "Disparities in Patient Reports of Communications to Inform Decision Making in the DECISIONS Survey." *Patient Education and Counseling* 87 (2): 198-205.

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