THE LAW, DEATH, AND MEDICAL ETHICS

A disability perspective from the United States on the case of Ms B

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This article will examine the case of Ms B, a woman with tetraplegia for a year, who, prior to rehabilitation or return to community life, sought a ruling that doctors may turn off her ventilator. The authors are people with disabilities. Their analysis focuses on the manner in which the High Court (a) framed the case in terms of mental capacity, (b) addressed the issue of suicide and ambivalence, and (c) resolved informed consent and treatment alternative issues. While the disability community in the US does not oppose the general right to refuse treatment, there is significant concern about lack of informed consent and denial of desired treatment alternatives, and the cavalier manner in which these factors have been dismissed.

In March, 2002, the High Court in London issued a ruling that Ms B, a 43 year old woman with tetraplegia who depended on a ventilator to breathe, had the mental capacity to direct that the ventilator be turned off, leading to her death.¹ Similar rulings were issued in several states in the US during the late 1980s, and confirmed for all states by the US Supreme Court in 1990. The perspective of the organised disability community on these cases has rarely been examined or seriously considered by the medical profession, the media, or the courts.

This article will examine the testimony of Ms B and the High Court's ruling through a lens forged in the disability rights movement, a movement based on the first-hand experience of people with disabilities who have found a positive identity as a social and political minority, in spite of broadly accepted and often crushing societal oppression. The authors are a woman with severe neuromuscular disabilities who uses a motorised wheelchair and a breathing machine at night, and a man with hydrocephalus who survived a physician's do-not-treat recommendation made at his birth.

While the disability community in the US does not oppose the general right to refuse treatment, there is significant concern about lack of informed consent and denial of desired treatment alternatives, and the cavalier manner in which these factors have been dismissed. The divergent professional and societal response to suicidal individuals with and without severe physical impairments is also a concern, particularly in that the divergence, or discrimination, is not acknowledged or questioned. The analysis below will

focus on the manner in which the High Court (a) framed the case in terms of mental capacity, (b) addressed the issue of suicide and ambivalence, and (c) resolved issues of informed consent and treatment alternatives.

MENTAL CAPACITY

The High Court began by confining itself to the issue of mental capacity:

It is important to underline that I am not asked directly to decide whether Ms B lives or dies but whether she, herself, is legally competent to make that decision.¹

The court then reviewed numerous authorities establishing the presumption of mental capacity and the almost absolute nature of the right to refuse treatment.

In *re MB (Medical Treatment)* [1997] 2 FLR 426, I said at 432: "A mentally competent patient has an absolute right to refuse to consent to medical treatment for any reason, rational or irrational, or for no reason at all, even where that decision may lead to his or her own death."¹

At no point does the court mention or discuss the fact that medical professionals frequently impose unwanted treatments on suicidal people, who are often summarily deemed mentally incapacitated simply because they are suicidal. In spite of the court's broad statement about the right to refuse treatment for any reason, "rational or irrational," it is more likely that the court made an unacknowledged judgment that Ms B's decision to die was more rational, due to the extent of her physical disabilities, than the suicidal acts of a physically healthy individual. As Dr Ian Bassnet, a National Health Service (NHS) physician with tetraplegia, commented in an opinion piece published on March 24 2002 in *The Observer*:

Most "able-bodied" people attempting suicide are assumed to be acting irrationally, but the rationality of disabled people desiring euthanasia or stopping essential life-sustaining treatment is not usually questioned in the same way.²

There can be little doubt that the High Court's unspoken assessment of Ms B's rationality is grounded, at least in part, in unquestioned assumptions about life with severe physical disabilities.

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In general, people believe that the more severe the disability, the more compromised the quality of life. There is scientific research that challenges this belief,³ but such evidence will not be considered if the belief is neither acknowledged nor questioned.

SUICIDE AND DISCRIMINATION

The High Court adopted without comment the common legal view that death by refusal of treatment is never suicide:

Lord Goff of Chieveley said at page 864

" ... On this basis, it has been held that a patient of sound mind may, if properly informed, require that life support should be discontinued: see *Nancy B v Hôtel-Dieu de Québec* (1992) 86 DLR (4th) 385". I wish to add that, in cases of this kind, there is no question of the patient having committed suicide, nor therefore of the doctor having aided or abetted him in doing so.¹

The disability community is far less absolute. There are many ways to commit suicide. The issue is the individual's motivation, not the method.

It is noteworthy that through pages and pages of Ms B's testimony, and the High Court's opinion, the only information elicited or reported concerning Ms B's interpersonal relationships was that she had an "unhappy childhood," an unsupportive family, was unmarried, had "a close circle of friends," and was devoted to her goddaughter. Ms B was apparently not questioned concerning such essential emotional matters as the amount of visitation by her loved ones, and how that might have changed over time, or any effects of her situation on her most primary relationships, such as that with a lover or best friend. These omissions, and others, demonstrate both abysmal ignorance of the experiences of severely disabled people, and a disturbing disinterest in exploring factors that might influence anyone to experience the hopelessness and despair that might lead to suicidal feelings.

Ms B stated in her testimony that she might make a different decision if she had children. She also rejected the option of a switch that she could operate herself to turn off her ventilator, expressing concerns about her goddaughter:

To her the notion that her godmother chose to commit suicide would be painful, and I know that is her feelings. But, because I love her, it matters to me.¹

Though later indicating that she would use such a switch as a last resort, taking Ms B's testimony as a whole, one is left with a sense of Ms B's ambivalence, an inevitable characteristic of suicidal feelings.

INFORMED CONSENT AND TREATMENT ALTERNATIVES

Among the authorities considered by the High Court was a 1990 state Supreme Court ruling in Nevada in the case of Kenneth Bergstedt.

One of the verities of human experience is that all life will eventually end in death. As the seasons of life progress through spring, summer and fall, to the winter of our years, the expression unknown to youth is often heard evincing the wish to one night pass away in the midst of a peaceful sleep. It would appear, however, that as the scientific community continues to increase human longevity and promote "the greying of America" prospects for slipping away during peaceful slumber are decreasing. And for significant numbers of citizens

like Kenneth, misfortune may rob life of much of its quality long before the onset of winter.⁴

As the High Court noted, Kenneth Bergstedt "was 31 years old and had been tetraplegic since the age of 10. As a result of the imminent death of his father who had cared for him, Kenneth wanted to be released from 'a life of paralysis held intact by the life-sustaining properties of a respirator'."¹ Although Bergstedt's father had turned off his ventilator after a lower court authorised him to do so, the Nevada Supreme Court did not treat the case as moot. Of significant importance, the Nevada court discussed the fact that Bergstedt was primarily fearful of being forced into a nursing home after his father's death, and noted that Bergstedt did not appear to be aware of home care alternatives that could keep him out of an institutional setting. Why did the High Court in London ignore this?

At the time of the High Court ruling, Ms B had spent a year in a hospital intensive care unit. Approximately seven months before the ruling, at a time when Ms B had been willing to consider the treatment alternative of rehabilitation, no bed was available in a rehabilitation facility. Some of Ms B's testimony pertained to the question of whether she could give informed consent to turn off her ventilator without having first experienced life in the community.

When asked about her views on rehabilitation, Ms B at one point stated:

My view is that it offers me no real opportunity to recover physically, that, in actual fact, it will be more teaching me to live with my disability and to make use of the technologies available and that sort of thing, working with the carers. But, actually, I will not recover in any way. That is not acceptable to me.¹

Questions concerning two brief experiences outside the ICU during the year are excerpted below:

Q. You have been able to get out, rarely, but you have been able to get out. Once I think you went, did you, to visit your home?

A. No, once I went out the back and just sat outside for 10 minutes. On another occasion I had a ride through the consultants' car park and round the hospital.

Q. That is as far as you have been?

A. I was out for about 20 minutes, half an hour, yes.

Q. That is when you had the use of the portable ventilator, was it?

A. That is right, yes. . . . Part of that rehabilitation programme included being seated in a chair and being taken out of the building on ventilator support. It was supposed to show me what was possible.

Q. Do you think it succeeded in showing you what was possible?

A. Oh yes.

Q. Even within such a very short space of time?

A. Obviously not. It is not the same as if I was in rehab and went out every day, but it got me outside, yes, and I saw the world from a wheelchair and I saw how people looked at me, yes.¹

From an informed disability perspective, Ms B's year in an intensive care unit, coupled with her first experience of the way people looked at her, speak volumes. Dr Bassnet, in the *Observer* article, provides an insightful account of his own experiences.

I was ventilator-dependent for a while and at times said to people: "I wish I was dead". I am now

extraordinarily glad no one acted on that. I think the first difficulty I faced was the fact that, like many people, I had a terribly negative image of disability. People are often scared or pitying. When you're suddenly severely disabled you still have that viewpoint, but you have a body with impairments that you previously felt very negative about . . .²

He then comments:

It would be presumptuous to believe that I knew that was how Miss B was feeling. However, in her evidence, she implies that being in that physical condition and seeing how people looked at her are among her concerns.²

To those of us with significant disabilities, it is obvious that Ms B was not provided with the time, opportunity or support to re-establish her identity and rebuild her life in a way that would counter the widespread negative social attitudes that are evident in the looks on people's faces.

Further testimony addressed practical issues about rehabilitation:

Q. What is it that stops you wanting to go and do it and then make up your mind?

A. Well, there are two things. (1) I know what it has to offer and I know that what I want it cannot offer. It offers me no chance of recovery. That is not disputed by anybody. (2) there has not been a place available anyway to try it. At a time when I was going through it here and would have tried it, there was no place. And I think there is a logistical problem that, once you go to rehab, if my views did not change, it would be extremely difficult to get to a position of having my ventilator withdrawn.¹

Obviously, the option of rehabilitation was not made available at a critical point in Ms B's decision making several months earlier. At the time of her testimony, Ms B was also concerned that if she tried rehabilitation she would not later be allowed to change her mind and refuse the ventilator, or would have to initiate court proceedings all over again.

The High Court's absolute affirmation of the right to refuse treatment would suggest that Ms B's concern on this point was not well founded, but there is no indication that she was given any assurances on this matter.

Financial resources necessary to support various rehabilitation options were also discussed:

Q. To what extent does your experience of, what I might describe as, resource difficulties play a part in your mind?

A. It always does in social care and health, I am afraid.

Q. I understand that. What part does that play in your thinking?

A. For me it is not the first consideration, but it would be untruthful to suggest that it is not part of it. One of the things I did was to talk to a very good adviser from the Citizens' Advice Bureau about a whole range of issues that would affect how I live in the community. He produced an enormous amount of information from welfare benefits to equipment, home care, all of that. So I have a pretty good idea of what is available. There is a difference between what is out there and what is achievable for someone in my position. I am not Christopher Reeves and I can't pay for everything. Do you see what I mean?¹

In view of significant evidence that Ms B did not have timely and meaningful access to rehabilitation treatment alternatives, it could be argued that she lacked the information to make a truly informed refusal of treatment. The High Court's opinion on these issues was surprisingly callous. Referring to the opinion of a consulting surgeon in spinal injuries, the court stated:

Mr G . . . accepted that Ms B had mental competence and his one reservation was his conclusion that she was unable to give informed consent, not because of a lack of capacity in general but her specific lack of knowledge and experience of exposure to a spinal rehabilitation unit and thereafter to readjustment to life in the community. Without that opportunity which might take up to two years to complete, Ms B did not have the requisite information to give informed consent. *On that aspect of his evidence, I have the gravest doubts as to its legal validity and indeed its practicality* (emphasis added).⁵

The court has concluded that it would be *impractical* to ensure that treatment alternatives are provided and that consent is truly informed for people like Ms B. But resource allocation is always a question of priorities, and what has really been found by the High Court is that people like Ms B are not worth the resources required.

CONCLUSION

Returning to Dr Bassnet:

The law in this case has turned on the issue of mental competence. A competent individual has the right to refuse treatment, which few would argue with. However, this does raise wider issues about how society values the lives of disabled people.²

Narrowing the legal issue to one of mental capacity, the High Court summarily dismissed her right to informed consent as impractical. At the time of writing, Ms B is dead. She did not get her chance at a new life in the community with technology and personal assistants acting under her direction and control. She will never know the new friends and colleagues who may have become part of her life, or the contributions she might have made.

When the High Court issued its ruling, *The Times* reported:

. . . [T]here was hardly a person in the courtroom who did not hope that she would be allowed relief from her living death.⁶

But the disability community mourns, for her and for the others with new disabilities whose lives will be lost based on this legal precedent.

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