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Jan Bernheim: a Pioneer/Prophet in Getting Serious Answers to the Serious Question 'How are you?'

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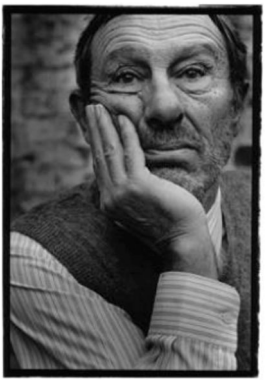

Jan L. Bernheim's main contributions to the quality-of-life field are his visionary work in developing imaginative, less conventional ways of measuring subjective well-being, and introducing palliative care in medical practice that progressed to 'integral end-of-life care', including assistance in dying.

Bernheim was born in 1941 in Brussels, Belgium, as Jean to his French father and Jan to his Flemish mother. She liked recounting that Jan's nocturnal birth was greeted by not forty, but by hundreds of cannon-shots as German flak took aim at RAF bombers. His Jewish father had to go into hiding in the Pyrenees. He survived but his marriage did not. Young Bernheim's grandfather, Louis E. De Mey (1876–1943), a pacifist and humanist social-democrat, was his role model. De Mey's writings in 1933 were prophetic of WWII and called for Europe's unification to avert war.

In 1968, Jan married Clara Castelyns, an archaeologist, with whom he raised five children, one an orphan. Two of their children were victims of disastrous medical negligence.

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Bernheim became a medical oncologist. He received his training in pathology and internal medicine at the Universities of Gent and Amsterdam (1966–1971), completed an internship at the University of Brussels Jules Bordet Cancer Institute (1971–1974) and was appointed assistant professor at the University of California, San Diego (1974–1977). Until his formal retirement in 2006, he taught clinical research methodology and medical ethics at the Vrije Universiteit Brussel (VUB).

Before Bernheim became a clinician involved in the medical humanities, he co-authored the first demonstration of cytotoxic lymphocytes in human melanoma. His PhD research included a description of what became known as apoptosis (programmed cell death).

Ahead of the Times: A Bit of a Visionary Bernheim was involved in Third World social development projects, including the promotion of family planning in Rwanda in the early 1980s, a decade before the 1994 genocide. His first teaching assignment was as lecturer in immunology at the Université Nationale, Butare. He did well, as his Rwandan students successfully passed the French translation of the standard multiple-choice examination for immunology. Yet his contract was not renewed when he refused to give up teaching family planning.

According to Bernheim, Rwanda's 'demographic catastrophe' was an underrated cause of the extent of the infamous genocide. There had been inter-ethnic bloodshed before, but 1994 was a hundredfold worse. Whereas maximal fertility was a reasonable means of herd survival in times of massive mortality, it becomes a scourge in times of vaccines and antibiotics. The Rwandan population doubled in 20 years, making excruciating land hunger the chief incitement for murdering neighbours. An estimated 200′000 perpetrators hacked 800′000 people to death. Never in history was the ratio of perpetrators to victims so high.

Pioneering Non-Conventional Approaches to Measuring Quality of Life As a clinician, Bernheim strove for a 'scientifically holistic' approach to treating his patients. He saw his patients as multi-faceted individuals, who deserve attention to their social, cognitive, emotional, and existential needs. This was a tall order, so his consultations tended to run late. Some of his seriously ill cancer patients even 'took their doctor along on vacation'! They would ask where Dr. Bernheim would be going on holiday, and then, with his consent, booked their holiday accommodation nearby to ensure continued care.

Because treatment of advanced cancer involves compromises between quantity and quality of life, and also comparisons between different treatments, Bernheim wanted to monitor how his patients really felt under his care. So he developed the Anamnestic Comparative Self-Assessment, later called Bernheim's ACSA, to avoid trivial or 'relative to circumstances' responses to the standard 'how are you?' question. He is

fond of illustrating trivial subjective well-being responses with a Jewish joke:

- Moische, how are you?
- Good.
- Good?
That's a bit short.
Tell me more,
in two words.
- Not good.

Could there be a scale with personal, concrete *internal* reference standards for subjective well-being? Several patients provided a clue: faced with life-threatening disease, they 'looked at the movie of their life', recounting their best and worst times. They thus defined the anchors of their individual and internal scale of subjective well-being, just what Bernheim needed. With ACSA, these best and worst anchors are rated +5 and − 5, respectively (Bernheim 1999).

The ACSA measure has proved more sensitive than the conventional global question on subjective well-being (Theuns et al. 2014; Bernheim et al. 2006). In clinical quality-of-life research, for instance, a bimodal distribution of subjective well-being showed ACSA overcame the 'disability paradox', i.e. the phenomenon that conventional instruments are incapable of observing difference between healthy and severely disabled people. Future longitudinal and interventional studies with ACSA may disprove the set-point theory of subjective well-being, according to which subjective well-being can only change very temporarily, because it is a trait or, as life circumstances change, so do expectations (the hedonic treadmill).

In multi-cultural South Africa, respondents from different population groups chose similar anchor points, probably human universals, demonstrating the cross-cultural validity of ACSA. This finding supports the notion that differences in subjective well-being between sub-cultures may reflect real material inequalities that also affect hearts and minds.

Together with co-workers, Bernheim achieved a number of firsts in the health-related quality-of-life field. He co-founded and first chaired the Study Group for Quality of Life within the European Organisation for Research on the Treatment of Cancer (EORTC). EORTC convened its first health-related quality-of-life conference in Brussels in 1980, which led to the formation of the International Society for Quality of Life (ISOQOL) and the launch of its journal *Quality of Life Research.*

End-of-Life Care Frontrunner In 1980, Bernheim co-founded the first palliative care organisation in continental Europe. He is known by many as the pioneer of the unique Belgian model of integral End-of-Life Care, which provides continuity of care from conventional palliative care to assisted dying (Bernheim and Raus 2017). The model was first introduced in the Dutch and French-speaking hospitals attached to the Vrije Universiteit Brussel/Université Libre de Bruxelles, that subscribe to secular humanism principles and had already pioneered contraception, abortion and assisted procreation. Their severely suffering patients may have felt freeer than patients elsewhere to request

assisted dying. It was an uphill battle, Bernheim recalls; prioritising *quality* over quantity of life went against engrained medical practice. Initially, hospital authorities were reluctant to accept palliative care, 'we want to be known as a place where no-one dies.' They initially rejected assisted dying 'because we have palliative care'. Bernheim plans to observe whether patients, promised assistance in dying, actually live longer than those dying conventionally.

In 2002, the Belgian parliament enacted twin bills assuring access to palliative care and assisted dying to all. The following year, the Federation of Palliative Care incorporated medical aid in dying into their practice, thus realising 'integral end-of-life care'. Abroad, Bernheim's testimony before Canada's high court was judged 'persuasive' when it legalised medical assistance in dying in 2015.

Academic Affiliations and Current Activities Bernheim is currently an emeritus professor and volunteer researcher in medical ethics, end-of-life issues and quality of life at the Vrije Universiteit Brussel (VUB). He is affiliated to the *End-of-Life Care Research Group* at the VUB and Ghent University, the Study Group *Evolution, Cognition and Complexity (ECCO),* the *Centrum Leo Apostel* for interdisciplinary research at VUB, and the *Coma Science Research Group* at the University of Liège. Current research also includes a procedural-ethics method to resolve conflicts between patient autonomy and physician beneficence.

Bernheim's publications include over 150 international peer-reviewed articles. They range from studies of cell death, to measurement of quality-of-life and end-of-life issues, and to global progress (see Wikipedia 2020). He regularly contributes to op-ed pages in the general press.

Bridge-Builder Bernheim's life work straddles the sciences and the humanities, health-related and societal quality-of-life studies. By integrating different approaches, his work has here and there changed medical practice. To take the measure of this, one may ask how many quality-of-life studies have similarly changed societal policies? In economically developed countries, objective factors proven to contribute to happiness are increasing, yet subjective well-being remains stagnant (Easterlin's paradox). Conventional quality-of-life instruments seem insensitive to objective progress. Might Bernheim's ACSA, with its universal autobiographical, 'trait-blind' anchors, transcend the hedonic treadmill? If so, ACSA would be a better measure of societal progress and encourage confidence in a better world.

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