

VIDEO INTERVIEW TRANSCRIPT

Hodgson, Shirley: transcript of a video interview (04-Nov-2015)

Interviewer: Tilli Tansey

Transcriber: Debra Gee

Editors: Emma M. Jones, Tilli Tansey, Apostolos Zarros

Date of publication: 08-Jun-2016

Date and place of interview: 04-Nov-2015; Queen Mary University of London

Publisher: Queen Mary University of London

Collection: History of Modern Biomedicine Interviews (Digital Collection)

Reference: e2016010

Number of pages: 7

DOI: 10.17636/01012730

Acknowledgments: The project management of Mr Adam Wilkinson and the technical support (filming and production) of Mr Alan Yabsley are gratefully acknowledged. The History of Modern Biomedicine Research Group is funded by the Wellcome Trust, which is a registered charity (no. 210183). The current interview has been funded by the Wellcome Trust Strategic Award entitled “Makers of modern biomedicine: testimonies and legacy” (2012-2017; awarded to Professor Tilli Tansey).

Citation: Tansey E M (intvr); Jones E M, Tansey E M, Zarros A (eds) (2016) *Hodgson, Shirley: transcript of a video interview (04-Nov-2015)*. History of Modern Biomedicine Interviews (Digital Collection), item e2016010. London: Queen Mary University of London.

Related resources: items 2016011 - 2016019, History of Modern Biomedicine Interviews (Digital Collection)

Note: Video interviews are conducted following standard oral history methodology, and have received ethical approval (reference QMREC 0642). Video interview transcripts are edited only for clarity and factual accuracy. Related material has been deposited in the Wellcome Library.

© The Trustee of the Wellcome Trust, London, 2016

Hodgson, Shirley: transcript of a video interview (04-Nov-2015)*

Biography: Professor Shirley Hodgson BSc BM BC DM D(Obst)RCOG FRCP DCH FRSB (b. 1945) began her career as a Paediatrician and General Practitioner. She became a Registrar in Clinical Genetics at Guy's Hospital, 1980, and worked with Professor Victor Dubowitz at the Hammersmith Hospital on muscular dystrophy whilst doing the work for her DM Thesis. She became a Consultant in Clinical Genetics at Addenbrooke's Hospital in 1988, and Consultant/Reader in Clinical Genetics at Guy's in 1990. She specialised in cancer genetics from 1989, working with the Imperial Cancer Research Fund (now Cancer Research UK), developing regional cancer genetics services at Guy's, St. Mark's and St. George's Hospitals in London. In 2003 she was appointed Professor of Cancer Genetics at St. George's, University of London, now Emerita, and has part-time Consultant status in Leicester. Her research investigated inherited aspects of cancer predisposition, she has published widely on the subject, and co-authored several books, including *Inherited Susceptibility to Cancer* (Foulkes and Hodgson (eds), 1998), and *A Practical Guide to Human Cancer Genetics* (Hodgson and Maher, 1993), now into its fourth edition with W. Foulkes and C. Eng as co-authors (Springer).

[1]. HOW AND WHY DID YOU BECOME INTERESTED IN SCIENCE?

I suppose I've always been interested in science, and particularly animals, and natural sciences and things like that. As a child I used to be very interested in my several pets including rabbits, mice and cats, of which I was very fond. So if they died, on a couple of occasions, I used to bury them in the garden, and then I used to go into the garden a few months later and dig them up and boil them, and pull off the flesh, and then I would string the vertebrae onto a coat hanger and so in my bedroom there was a little display of skeletons of animals. So, I used to like finding out how things worked. And also my father used to do interesting scientific things with me, like he helped me make a little radio out of a cat's whisker and a little crystal and I thought that was really fun. So I've always been sort of interested in science, and I had quite a scientific family so that sparked me off, although I did want to be a ballet dancer most of the time when I was young.

My father was Lionel Penrose and his wife was Margaret. They were both doctors and in fact they met at Medical School. My father was a well renowned geneticist, but my mother didn't really work. They were very hospitable and had a lot of friends who were academic geneticists and so on and the house was always full of fascinating people. That was one of the really exciting things about growing up in that family; some people would come and stay for several years sort of 'by chance'. I remember once we couldn't find any hot water bottles and we found that there was a chess player staying in the attic and he had about 12 hot water bottles in his bed. So that sort of thing used to keep us amused. But yes, my father was very well known for being a pioneering geneticist and also for his views against eugenics, which was a very prevalent thing at the time. He sort of pioneered clinical genetics, modern genetics. He did a lot of work on the origins of mental retardation, on the causes of mental retardation, and also the age at which mothers were when they had their children, they were more likely to have children with Down's syndrome if they were older. And things of that nature. He was very innovative in many fields and made many original observations and discoveries. He was also a very strong anti-eugenics person, so he had a lot of ethical views on the way genetics was used.

* Interview conducted by Professor Tilli Tansey, for the History of Modern Biomedicine Research Group, 04 November 2015, in the School of History, Queen Mary University of London. Transcribed by Mrs Debra Gee, and edited by Ms Emma M. Jones, Professor Tilli Tansey and Dr Apostolos Zarros.

[2]. BECOMING A CLINICAL GENETICIST: FROM GENERAL PRACTICE TO GUY'S

Having decided not to be a ballet dancer rather reluctantly, I then went into science as a student and then to medical school and so on. And then because I had young children I decided they were the first thing in my life and I was going to work part-time, for a long time and I never really thought I wanted to do genetics I didn't think of studying genetics, because clearly having a father who was so well known for his genetics career, I thought I'd better do something different. So I became a GP [General Practitioner], but fell foul of the particular GP practice I was working with, which was a very evangelical religious practice, and when they found that I was prescribing contraceptive pills to unmarried girls they got very angry and they gave me the sack. My husband, who has always been incredibly supportive throughout my whole career, which has been very important to me, spotted a very tiny advert in the newspaper for a locum in the Paediatric Research Unit as it was then called, at Guy's under Professor Polani, in clinical genetics, and I applied and I got that job. And at once, the minute I started, I thought it was just completely fascinating. So I couldn't escape after that.

I worked part-time for at least 12-14 years, I guess. I always felt that the children came first and I had difficulty ever letting anybody else look after them. But I did work part-time and it was very important to me that my husband was always incredibly supportive and helpful; and you know he used to help me find new jobs and new ways to work round obstacles so that I could do what I wanted to do. So that's been really important in my career, I think.

[3]. CLINICAL GENETICS: DUCHENNE MUSCULAR DYSTROPHY AND CANCER

Okay, I did the locum for Paul Polani and I just thought the whole thing was completely fascinating, and I was sort of caught, hook, line and sinker. I thought it was a wonderful sort of combination of really interesting intellectual puzzles and the ability to talk to patients, explaining these concepts, and to look after families and so on. It was a wonderful combination of things. And I really wanted to do it then, to follow a career in clinical genetics, but the problem was I couldn't because I hadn't taken Membership exam yet, so I had to go back into paediatrics. I did paediatrics as a registrar in Chase Farm Hospital for two or three years and then got my Membership exam. Then I went back to do a research job at Guy's again, and I worked also at the Hammersmith Hospital on Duchenne muscular dystrophy with Professor Dubowitz, and did my DM thesis there. Of course, the exciting thing at that time was that scientists were just finding the gene that caused Duchenne dystrophy when it was mutated, and then we were able to look at the different mutations in that gene, and the different degrees of disease which were caused by the different mutations, and that became very fascinating in terms of finding out what made some mutations have a more severe effect than others. Also we used this knowledge to develop molecular tests to help the families and offer them prenatal tests, and it was a great help to the families to have this extra ability to test for carriers and so on. That was very exciting and a very exciting moment.

After that I went back to work at Guy's as a Clinical Genetics Registrar, and then went as a Consultant to Cambridge. At that time cancer genetics was just sort of 'waking up'. People were becoming aware that a family history of cancer was associated with your risk of cancer, and that you could correlate the degree of a person's family history of certain types of cancer with their degree of risk of that cancer, and start working out which sorts of people had a sufficiently high risk to be screened for it certain cancers. Also of course the genes for the conditions causing these strong cancer predispositions were beginning to be located. I became very interested in cancer genetics, partly because I felt that was more 'useful' in a sense, than perhaps some of the other clinical genetics that I'd been doing, in terms of potentially saving lives or preventing health problems. At that time I was working with Eamonn Maher, who was a bright new Registrar at Cambridge, and who has turned out of course to be a very excellent Professor of Genetics now. Together we wrote the book called *A Practical Guide to Human Cancer Genetics*, which I think was pretty much the first handbook of cancer genetics for clinicians and clinical geneticists about cancer genetics. So I felt that was important to me to have been able to help pioneer this aspect of clinical genetics.

I came back to London to work at Guy's as a Consultant in Clinical Genetics in 1992, but more on the academic side, so I also did research, and I was very fortunate to have grant money from the Imperial Cancer Research Fund with encouragement from Sir Walter Bodmer, who was very supportive during those years. This provided me with funding for a series of Research Registrars who came and did various different projects in the area of translational cancer genetics. Quite a lot of this was molecular work, not all of it, and some clinical, so we then became able to sort of "translate" the molecular work into a service for the patients. And *vice versa*, sometimes the patients provided the most important resource for research. So it was a very important area to be in the middle of. I did that as part of my work as an academic at Guy's, but I was also running the South East Thames Regional Genetics Service. So when I went to St. George's in 2003 to a personal Chair of Cancer Genetics, I took over the South West Thames Regional Cancer Service, so that went on for about 10 years or so until I partly retired in order to be able to spend more time in Namibia, when we started going there to help develop the clinical teaching curriculum in the Medical School.

[4]. CANCER GENETICS: A PERSONAL STORY AND MEMORABLE PATIENT

I suppose the thing that sort of catapulted me into cancer genetics was a very personal story. My husband, being a gastroenterologist, was looking after a young woman who had colon cancer and he found out, she was, I think, in her forties or so, and she'd already had uterine cancer. He mentioned it to me, saying how odd this was, and he also said she looked a bit like my cousin's wife. He eventually talked to her and it turned out that she was my cousin's wife's mother. At that time it wasn't really very well known about Lynch Syndrome and that kind of thing, but I did know about Lynch syndrome and I knew that Joan Slack was running a clinic at St. Mark's Hospital where she assessed people's family histories and so on and arranged screening if she thought they were at an increased risk of colon cancer mainly, but she did also arrange gynaecological screening for women in those 'Lynch syndrome families'. Although the efficiency of that kind of screening hadn't really been established at all, although she had established a bit of the efficacy of screening for colon cancer.

So anyway it took me rather a long time to screw up my courage to ring up my cousin's wife to talk to her about this because I thought it was a bit intrusive, but eventually I did, and she was actually amazingly receptive. I remember exactly where I was sitting at the time. And so she agreed to go and see Joan Slack, and Joan said, 'Oh yes, you probably ought to be screened.' And so indeed she was put on the ladder for screening, but when she was scheduled for colonoscopy it turned out she was pregnant, so everything got put back by 9 months, so that all took rather a long time to get organised. After she'd had the baby she returned for a colonoscopy, but developed symptoms of ovarian cancer, which was subsequently diagnosed, and tragically she died. So of course that was very, very shattering, and actually if you can be sort of disconnected from what you feel about it, it was quite interesting later on when we did see the whole family for genetic counselling, that it turned out that they had a huge family history of cancer, but nobody had ever thought about it in terms of whether it meant that they were at increased risk of cancer or not. So that previous knowledge about the importance of family history of cancer hadn't really got above the surface.

[5]. ACHIEVEMENTS AND REGRETS?

Well, okay, I guess probably the most important achievement of my career is the writing of the book, which is a handbook of cancer genetics, clinical cancer genetics. It's called *A Practical Guide to Human Cancer Genetics* and it was me and Eamonn Maher initially, although now it's gone into its fourth edition and it's now with four author/editors. We did dedicate it to my cousin who had died of ovarian cancer with a family history that conformed to Lynch syndrome.

I guess one of the things I always did regret from an academic point of view is that I never spent any significant amount of time in the laboratory doing laboratory work. So that whenever I had Research Registrars working with me I had to farm them off to other people's laboratories in order to go and to be supervised to do the molecular work that we wanted to do. I understood the methods we wanted to use but I used to have to get them mentored by colleagues who I knew about these things. I'd always been too

impatient to go and do the laboratory work myself when I was training because I'd much rather be looking after patients than sitting in a lab with test tubes.

[6]. DEVELOPING MEDICINE IN NAMIBIA AND IRAN [PERSIA]

We had known Eldryd Parry [of THET; Tropical Health Education Trust] for a long time and I've always been interested in trying to help with medicine in the Third World, as opposed to relatively well-off places like England, although you could say that rapidly we're becoming Third World now ourselves. But anyway, I'd spoken to Eldryd about my wish to go and do something useful in medicine in the Third World and he also knew that Humphrey, my husband, was. Eldryd received an email from the Dean of the new Medical School in Namibia. They'd just set up the first and only Medical School there about three years previously at the request of the government; the country became independent in 1990. They needed a Medical School because they had no home-grown doctors of their own, so clearly this was important to them. So they had started a Medical School which had, for the first three years, been covering the preclinical work, anatomy, physiology, biochemistry and all of that, which was beautifully done. Then they had to develop a clinical curriculum and needed someone to develop this for Internal Medicine, so Eldryd suggested Humphrey for this task. There was a need to work with the hospitals and the local doctors, to try and set up a link so that the students could learn the clinical aspects of medicine. And so we went over to visit and they asked me what I trained in. I said, 'I trained in paediatrics,' so they asked me to develop the paediatrics curriculum. So we agreed to go four months each year to set up the clinical curriculum, which was really exciting and challenging, and hopefully now it's running on its own.

Previously when we were first married we went on an exchange to Iran [Persia], where we were working as Residents, and clearly it was a bit difficult because we didn't speak the language. But we did learn what they called 'medical Farsi' so if you'd like me to ask you whether you're vomiting blood, I can do that in Farsi, but can't say very much else. It was arranged through a link that one of the doctors at St. Thomas' Hospital, where my husband was working, had. Various people from St. Thomas' Hospital had gone out there before. We lived in Shiraz and we had a wonderful six months working there in the hospital and also we had the opportunity to visit some parts of the country as well, which was really exciting.

[7]. DEVELOPING CANCER GENETICS SERVICES IN CHINA

Recently I've had some enquiries from a Chinese colleague who I met many years ago when she was a clinician working in the Hammersmith Hospital when my husband was at the Hammersmith. I got to know her then and now many years later she's back in China and working there, but she's become aware of the huge discrepancy in China between their amazing ability to do molecular, technical things, and translate this to the clinic. They can sequence any gene you like, and genomes, and they get all the data beautifully, but they don't have the clinical knowledge and structure with which to use this information in the clinical setting, and discuss these results and their implications with patients. So they have started making enquiries from people in England and I'm sure elsewhere to try and get some help with developing their clinical genetics services from the genetic counselling perspectives so that they will be able to marry up their clinical counselling abilities with all this amazing technology that they have.

Of course China is a very large country and from what my colleague was saying, it does sound as though they would like travelling teaching course, to go around teaching short courses on cancer genetic counselling, or general genetic counselling indeed, in various parts of China. So clearly that's an enormous job. On the other hand, it's really nice to be involved with that kind of thing and it's very flattering to be asked and it would be nice to set up that kind of collaboration. So I've been talking to people from the Department of Trade and Industry in the UK to see how we could take this forward on a big scale. But this would really need to be set up at a government to government level, which clearly there is a structure to do here. So we're beginning to enter into discussions which would promote the development of that kind of teaching mode.

[8]. ADVANCES OVER THE PAST THIRTY YEARS?

It's been an incredibly exciting time because with the discovery of the genes for Lynch syndrome and the genes for breast cancer susceptibility, we've learnt a huge amount, not only that can be used for genetic testing and counselling and to be able to identify people at high risk but also learn about the mechanisms by which these cancers develop. We now know details of many genes with smaller effect that have additive effects on risk and can get much improved risk estimates using information on a panel of genes.

Also we are able to do a sort of fingerprint of all the different mutations in different cancers and we're discovering that different cancers may be completely different in terms of the molecular mechanisms and pathways that have been triggered. So we can learn about the triggers and we can learn about the way the pathways develop and we can then learn about the way that you would be able to treat these different cancers and different cancer types based on the knowledge of the different mutations of those different cancers. So it's a huge advance both for treatment and for diagnosis.

[9]. THE NEXT THIRTY YEARS?

I think in the next 20-30 years things are going to change hugely. It may be that we will be able to use the CRISPR [clustered regularly-interspaced short palindromic repeats] technique now that's being developed to chop out genes that are faulty and pop in the normal one, and treat diseases in that way. I think probably a lot of genetic diseases will be a lot more treatable. I think possibly preimplantation treatment may be a possibility so there are huge, huge advances to be made and genetics will now become something which is practiced by everybody and not just the geneticists, so it's going to be part of general medicine, I think. Also cancers will be much more amenable to treatment.

I think the discovery of the Duchenne gene was really important and it just happened in the middle of my research so that suddenly instead of just saying to women who'd had a child with Duchenne, 'you might be a carrier and you might have another child with this same absolutely devastating disease' and she might say, 'I won't have sons at all so I will terminate all my male pregnancies in the future' it's a pretty terrible thing, because she would know that at least half of those boys would be fine. So with the advent of finding the mutation, we were then able to test in a pregnancy to see whether the boy might have Duchenne dystrophy or not, so clearly that was a huge benefit. And we were also able to refine the estimates of risk of being a carrier for the mothers. And the other aspect of that was that we found that a lot of the mutations in the gene were deletions, and I remember it took us a long while to work out why different deletions caused the milder form of Becker as opposed to the most severe type of Duchenne dystrophy. And at first it didn't seem to have any relationship to the type of, to the size of the deletion, but then it became apparent that the deletions that then interrupted the reading frame were the ones that caused the severe disease, and that was again something really amazing.

[END OF TRANSCRIPT]

Further related resources:

1. Foulkes W D, Hodgson S V (eds) (1998) *Inherited Susceptibility to Cancer: Clinical, predictive, and ethical perspectives*. Cambridge; New York: Cambridge University Press.
2. Hodgson S V, Maher E R (1993) *A Practical Guide to Human Cancer Genetics*. Cambridge: Cambridge University Press.
3. Jones E M, Tansey E M (eds) (2013) *Clinical Cancer Genetics: Polyposis and familial colorectal cancer c.1975-c.2010*. Wellcome Witnesses to Contemporary Medicine, vol. 46. London: Queen Mary University of London.
4. Jones E M, Tansey E M (eds) (2016) *Medical Genetics: Development of Ethical Dimensions in Clinical Practice and Research*. Wellcome Witnesses to Contemporary Medicine, vol. 57. London: Queen Mary University of London.
5. Reynolds L A, Tansey E M (eds) (2010) *Clinical Genetics in Britain: Origins and development*. Wellcome Witnesses to Twentieth Century Medicine, vol. 39. London: Wellcome Trust Centre for the History of Medicine at UCL.

6. Tansey E M (intvr); Jones E M, Tansey E M, Zarros A (eds) (2016) *Hodgson, Shirley: transcript of an audio interview (04-Nov-2015)*. History of Modern Biomedicine Interviews (Digital Collection), item e2016009. London: Queen Mary University of London.