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How wide is the Goldilocks Zone in your health system?

Abstract

In astrophysics the ‘Goldilocks Zone’ describes the circumstellar habitable zone, in which planets, sufficiently similar to Earth, could support human life. The children’s story of *Goldilocks and the Three Bears*, one of the most popular fairy tales in the English language, uses this metaphor to describe conditions for life that are neither too hot, nor too cold, neither too close to the sun, nor too far from its warmth. We propose that the ‘Goldilocks Zone’ also offers an apt metaphor for the struggle that people face when deciding if and when to consult a health care provider with a possible health problem. Drawing on decades of research in Denmark, England and Sweden on people’s accounts of their experiences of accessing health care, this Essay considers the ambivalence of health care seeking that individuals face in identifying when it is ‘just right’ to consult a general practitioner, and the steps that health systems and individual clinicians might take to widen the zone.

Introduction

It is well known that the experience of an unfamiliar bodily sensation, even if troublesome, does not necessarily predict whether or not someone will consult a doctor. The medical humanities and the social sciences have drawn attention to the many factors in the people’s lifeworld that influence a decision to seek medical help.^{1,2,3} These illuminate why people may not consult with bodily sensations that health professionals would consider to be ‘worrying symptoms’. As social sciences and health care researchers, with many years’ experience of fieldwork-based studies in Denmark, England and Sweden, three northern European health systems, we have been struck by the difficulties that people recount in trying to determine whether and when they should consult. In this Essay, we argue that there are tensions and ambivalence in deciding how to behave as a ‘good citizen’ in relation to health care. Such ‘behaviours’ have been encouraged by contemporary health systems that are increasingly stretched for resources. We propose that these tensions and ambivalences are not inevitable features of the patient-doctor relationship and could be ameliorated through some relatively simple shifts in practice.

Sociological ambivalence

Ambivalence is a familiar experience: we may hold contradictory views on a topic, have difficulty choosing between different courses of action, or experience simultaneously positive and negative emotional reactions. In their 1963 essay, Merton and Barber took a sociological perspective on *'the ways in which ambivalence comes to be built into the structure of social statuses and roles'*.⁴ Ambivalence, they propose, is not simply an inevitable response to having options but *'directs us to examine the processes in the social structure that affect the probability of ambivalence turning up in particular kinds of role relations'* (p. 5).⁴ They argue that ambivalence sheds light on the contradictory norms and expectations of relationships within a social structure. Health care provides telling examples in this regard, and in *The Ambivalence of Physicians*,⁵ Merton (who was writing in the USA) described nine potentially conflicting norms governing the physician – patient relationship, including¹:

Physicians must be emotionally detached in their attitudes towards patients, keeping 'emotions on ice' and not becoming 'overly identified' with patients BUT they must avoid being callous through excessive detachment, and should have compassionate concern for the patient.

*Physicians should institute all the scientific tests needed to reach a sound diagnosis BUT they should be discriminating in the use of these tests, since they are often costly and may impose a sizable financial burden on patients (p. 68).*⁵

Drawing on examples of research in Denmark, England and Sweden,^{6,7,8,9,10,11} and the example of Merton's identified ambivalences we suggest that similar *patient ambivalences* exist, with consequences for health care seeking practices. Box 1 illustrates some of these contradictory norms which govern citizen interactions with the health care system .

Box 1 Contradictory norms governing citizen interactions with the health care system

- The good citizen is attentive to their health and alert to bodily changes *but* not obsessed with their own health to the point of hypochondria or being 'worried well'
- The good citizen respects the doctor's time and recognises that there are pressures on the health system *but* does not delay seeking help
- The good citizen responds to media campaigns to increase symptom awareness *but* does not present unnecessarily nor too often

- The good citizen accepts the doctor's reassurance about the low likelihood of a serious health problem *but* also listens to their own body and is prepared to challenge advice if the symptom persists or worsens
- The good citizen trusts experts *but* recognises and accepts personal responsibility for own health

The roots of patient ambivalence

People generally tend to seek assistance for concrete problems that they believe doctors can help them solve, and that doctors, genially, are disposed to help. Yet, people and their doctors meet within socio-political structures that convey ambivalence about what is the right thing to do and when to do it. Dixon-Woods and colleagues describe the tensions inherent in negotiating whether a problem is appropriate for medical attention. They suggest that the individual's struggle to assess whether they should seek health care for any given problem may present particular difficulties for the socio-economically vulnerable.³

Health care seeking practices unfold in accordance with the various social commitments that make up peoples' lives. We now turn to consider four structural roots which contribute to people's ambivalence about seeking care. ~~These are XXXX.~~ These structures are embedded in the micro-management of everyday life worlds and are evident in modern health care decisions and encounters.

First, medical practice is continually changing, involving increasingly specialised knowledge and space for technology. As discussed by several authors, ideals of prevention which encourage 'early and timely care-seeking' are characteristic of contemporary medicine that is predominately focused on biotechnology.^{12,13} Today's 'biotech-medicine' saves lives, and it has also taught us that diseases can be hiding (or are on their way) beneath the surface of the body and show none or only minor sensuous revelations of their existence. This challenges confidence and certainties about the 'health' of one's body, making it difficult to know with what and when to consult. Research includes ample illustration of the challenges that people face in determining when bodily sensations may be viewed as signs of disease requiring consultation:^{14,15, 8,16.} Is this 'mole' changing shape? When is tiredness or a pain sufficiently burdensome to justify consultation? How easy is it to negotiate time away from work to attend an appointment? Is this to be expected at my age? Aware of the importance of early investigations and intervention, people may seek speedy investigations and interventions. ~~At the same time,~~ In contrast, the considerable public awareness of the adverse consequences of certain cancer treatments may deter people from seeking care.

Second, so-called 'neoliberal values' in Northern European countries encourage individual responsibility for health as a core tenet.¹⁷ Research suggests that people living in the European North are aware that they are expected to be well informed, self-managing and 'responsible' users of publicly funded health and social care resources.^{11,15} In a recent cross-country comparative study of patients' accounts of their experiences leading up to a cancer diagnosis interview participants referred approvingly to 'healthy' behaviours such as being physically active, eating healthy foods and avoiding heavy drinking or cigarette smoking.¹⁸ They also suggested that it is appropriate to self-manage a problem as far as possible, and be responsible for their own health. Yet people's engagement with their self-care and the health care system can also demonstrate to them the limits to which they can affect their own health and life.¹⁹ It is usually the clinicians and health care system, and not individual patient, who have the authority or means to provide access to treatments and other resources.²⁰

Third, state regulation is increasingly present in the micro-management of clinical encounters. Regulation (or bureaucracy) may help ensure equal rights for citizens; for regulating expenditures, ensuring transparency and standardisation of treatment procedures. However, research suggests that increasing regulation and demands for standardisation in, for example, cancer referral pathways, may produce fragmented and rushed clinical environments,¹³ which feed into how people seek medical advice. In our research we increasingly witness how issues of *access* are used to legitimize health seeking behaviours, to find appropriate symptoms which qualify for a consultation.²¹ Those individuals who struggle to legitimize their health service use may feel they are placing unreasonable claims on the doctor's time.^{18,22} or the health system's resources. Any symptom that could be plausibly attributed to minor or self-limiting illness would run the risk of attracting an unwanted label (as a frequent flyer, heart-sink patient, hypochondriac) which people suspect, probably correctly, may affect their treatment as a 'sensible' person.

Fourth, medical knowledge has e-scaped, as aptly coined by Nettleton.²³ Health information, advice and, to some extent, treatment services have been transformed into global digital commodities, providing new ground for various private actors to offer advice on diet, birth, cancer cures and so forth. ~~Even~~ Anyone, including those with very rare conditions can share experiences, learn from each other, build relationships, learn how to access health services, gather information to inform treatment decisions, use their own knowledge to support others and find new ways to visualise and communicate their illness.²⁴ But this proliferation of opportunity also provides the channel for people to sell, or be sold, 'crack-pot' cures, to be misled, misinformed, or to learn how to manipulate the system.²⁴ A recent study of people seeking referral to a specialist within the English National Health Service (NHS) suggested

that hospitals are straining to accommodate people with ‘cyberchondria’ caused by people looking up their symptoms online.²⁵

Overall we assert that people in Europe are governed by contradictory norms into health care seeking. Following Merton, these can be expressed as core ambivalences in their interactions with the health care system (Box 1). This brings us to the Goldilocks Zone, which we find an apt metaphor for the struggle that people face when deciding if and when to consult with a possible health problem.

The Goldilocks Zone

In the children’s story ‘Goldilocks and the Three Bears’, the eponymous young heroine finds a house in the woods whose occupants (mother bear, father bear and baby bear) have taken a morning walk while waiting for their porridge to cool. The girl samples the three bowls of porridge that she finds on the kitchen table and then consumes the one that is neither too hot nor too cold. Exploring the house, she then samples the variously sized and upholstered furniture until she finds a chair that is neither too large nor too small and the bed that is neither too hard nor too soft. Goldilocks is confident (at least until the family of bears reappear) that each of the choices she has made is ‘just right’.

In planetary astronomy, the ‘Goldilocks Zone’ refers to a planet orbiting its sun at just the right distance for liquid water to exist on its surface, neither too hot nor too cold. We suggest that the Goldilocks Zone metaphorically illuminates the difficulty facing people when seeking the behaviour that is ‘just right’ for health care use. The person who manages the Goldilocks Zone is she who takes responsibility for her own health, but does not ignore the bodily changes that may be symptoms of disease, for which a consultation might be sought. It is she who finds it appropriate to self-manage her problems as far as possible, assessing what is ‘worth mentioning’ to the doctor, but also avoids wasting the doctor’s time, listens to advice, and avoids self-diagnosis while simultaneously navigating the increasing proliferation, commodification and uncertainty of health information.^{15, 17, 26}

It could of course equally be argued that the ‘should I, shouldn’t I?’ tension around consulting a doctor has a useful function and that a broader Goldilocks Zone would lead to *more frequent* health service utilization and, ultimately, an over-burdened system.

Intriguingly, in the countries of the authors, OECD data for per capita consultations in Sweden are lower than in Denmark or England. Indeed, of the three countries, England (where patients express more reluctance to consult) has the greatest number of GP consultations per capita per annum, albeit these are typically of a shorter duration than those in Sweden, for example.²⁷ Which raises the question: could comparing patients’

experiences in different countries shed light on whether there is a Mertonian sociological ambivalence, with wider implications for health policy and practice?

Comparing Goldilocks Zones

Drawing on our own research we suggest that the width of individuals' Goldilocks Zone for seeking health care may differ between countries. We also observed differences in the moral language that people use to describe the dilemma whether they 'should' consult, emphasizing that health care seeking is positioned as a moral process which requires (the performance of) an appropriate use of public resources.¹⁵ Health care structures, policies and what happens in the consultation itself frame the moral positioning of health care seeking. Reflecting on the roots to patient ambivalence outlined above, we suggest that the following may help to broaden the Goldilocks zone.

First, a truly person centred health care system should be responsive when someone decides that they need to consult. People need clarity and guidance from a responsive health system. Clinicians need to claim the time to 'contextualise' an individual's understanding and knowledge of sensations, symptoms, diagnosis and treatments.²⁸ This may challenge the contemporary focus in health care on efficiency and standardisation. But such an approach is not only important to ensure free and equal access, it could also reduce the need for repeat consultations and offer other beneficial consequences for patient experience and safety as well as health system efficiency.

Second, there is a key role for 'safety netting',²⁹ which is a strategy designed to ensure that people who present with symptoms that could be associated with a serious illness are monitored until an explanation for their symptoms is reached. Safety netting includes clear communication from the health care professional about what should happen next.¹⁷ Patients need to know if and when they should return for a consultation and to feel confident that they are not risking their moral identity when they do so. General practitioners in England often assume that if the patient has a persistent problem they will return; yet they may also be aware that patients reasons for consulting, or not, are often complex. Patients often feel discouraged from consulting again with the same problem. Those who are socio-economically disadvantaged may experience a higher disease burden, but also more difficulty in assessing eligibility (the 'doctorability' of the problem) and navigating access to care.³ We suggest, therefore, that the responsibility for safety netting needs to be located squarely within the health care system.

Third, it has long been recognised that doctors have to learn to handle the uncertainty that is an inherent part of any clinical practice.³⁰ General practitioners are familiar with uncertainty, even if they might disagree about the extent to which it should be ‘embraced’³¹ or avoided.³² We recommend that uncertainty should be acknowledged and shared with the patient and that action plans are clearly communicated at the close of the consultation. This may be particularly important when neither party is markedly concerned about the person’s health or the potential meaning of particular signs and symptoms.

Finally, we encourage the use of cross country comparisons, drawing on routine data along with quantitative and qualitative research,³³ which can illuminate the modifiable features in different health care systems,³⁴ guiding practice and policy initiatives to widen the Goldilocks Zone for people seeking health care. We need to make it easier for people to feel confident about how to make responsible use of a publically funded health system.

References

¹ Good B. *Medicine, rationality and experience: An Anthropological Perspective*. Cambridge University Press, 1994.

² Wyke S, Adamson J, Dixon D, et al. Consultation and illness behaviour in response to symptoms: A comparison of models from different disciplinary frameworks and suggestions for future research directions *Soc Sci Med* 2013; 86: 79–87.

³ Dixon-Woods M, Cavers D, Agarwal S, et al. Conducting a critical interpretive synthesis of the literature on access to healthcare by vulnerable group *BMC Med. Res. Method.* 2006; 6: 1.

⁴ Merton RK. *Sociological Ambivalence and other essays*. The Free Press, New York. 1976.

⁵ Merton RK. The Ambivalence of Physicians in ‘*Sociological Ambivalence and other essays*. The Free Press, New York. 1976.

⁶ Chapple A, Ziebland S and McPherson A. Qualitative study of men’s perceptions of why treatment delays occur in the UK for those with testicular cancer. *Br J Gen Pract*, 2004; 54(498), pp.25–32.

⁷ Levealahti H, Tishelman C, Ohlen J. Framing the onset of lung cancer biographically: Narratives of continuity and disruption. *Psycho-Oncology* 2007; 16: 466–473.

⁸ Andersen RS, Vedsted P, Olesen F, et al. Does the organisational structure of health care systems influence care-seeking decisions? A qualitative analysis of Danish cancer patients’ reflections on care-seeking. *Scandinavian Journal of Primary Health Care* 2011; 29:144–149.

⁹ Evans J, Chapple A, Salisbury H, et al. “It can’t be very important because it comes and goes”—patients’ accounts of intermittent symptoms preceding a pancreatic cancer diagnosis: a qualitative study. *BMJ Open*, 2014; 4:e004215.

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- ¹⁰ McLachlan S, Mansell G, Sanders T, et al. Symptom perceptions and help seeking behaviour prior to lung and colorectal cancer diagnoses: a qualitative study. *Fam Pract* 2015; 32(5): 568–577.
- ¹¹ Hajdarevic S, Schmitt Egenolf M, Brulin C, et al. Malignant melanoma – Gender patterns in care seeking for suspect marks. *Journal of Clinical Nursing*, 2011; 20, 2676–2684.
- ¹² Rose, N. *The Politics of Life Itself: Biomedicine, Power, and Subjectivity in the Twenty-First Century*. Princeton University Press. 2007.
- ¹³ Rosenberg, CE. *Our Present Complaint: American Medicine, Then and Now*. Baltimore: Johns Hopkins University Press, 2007.
- ¹⁴ Corner J, Hopkinson J, Roffe L. Experience of health changes and reasons for delay in seeking care: A UK study of the months prior to the diagnosis of lung cancer. *Soc Sci Med* 2006; 62: 1381-1391.
- ¹⁵ Llanwarne N, Newbould J. et al. Wasting the doctor's time? A video-elicitation interview study with patients in primary care. *Soc Sci Med* 2017; 176,113-122.
- ¹⁶ Offersen SMH, Vedsted P, & Andersen RS. ‘The Good Citizen’: Balancing Moral Possibilities in Everyday Life between Sensation, Symptom and Healthcare Seeking. *Anthropology in Action*. 2017 24/1, p. 6-12.
- ¹⁷ Lupton D. *Medicine as Culture: Illness, Disease and the Body* (revised 3rd edition). London: Sage. 2012.
- ¹⁸ MacArtney JI, Malmström M, Andersen RS, et al. Patients’ initial steps to cancer diagnosis in Denmark, England, and Sweden: what can a qualitative, cross country comparison of narrative interviews tell us about potentially modifiable factors? *BMJ Open* 2017; 7.
- ¹⁹ MacArtney J. Balancing exercises: Subjectivised narratives of balance in cancer self-health, *Health*, 2016 20(4), 329–345.
- ²⁰ Berlant L. *Cruel Optimism*. Duke UP: Durham, NC. 2011.
- ²¹ Andersen RS, Vedsted P. Juggling efficiency. An ethnographic study exploring healthcare seeking practices and institutional logics in Danish primary care settings. *Soc Sci Med*. 2015 Mar; 128:239-45.
- ²² Whitaker KL, Cromme S, Winstanley K, et al. Emotional responses to the experience of cancer ‘alarm’ symptoms. *Psychooncology* 2016; 25(5): 567–573.
- ²³ Nettleton S, & Burrows R. E-scaped medicine? Information, reflexivity and health. *Critical Social Policy*, 2003 23(2), 165-185.
- ²⁴ Ziebland S. Wyke S. Health and illness in a connected world: how might sharing experiences on the internet affect people’s health? *Milbank Q* 2012; 90 (2) 219-249.
- ²⁵ Tyrer P, Salkovskis P, Tyrer H, et al. Cognitive-behaviour therapy for health anxiety in medical patients (CHAMP): a randomised controlled trial with outcomes to 5 years. *Health Technol Assess* 2017;21(50).
- ²⁶ Evans J, Ziebland S, and McPherson A. Minimizing delays in ovarian cancer diagnosis: a reworking of Andersen’s model of ‘total patient delay’. *Fam Pract*, 2007 24(1), pp.48-55.

²⁷ OECD/EU. Health at a Glance: Europe 2016: State of Health in the EU Cycle. Paris: OECD Publishing 2.

²⁸ Andersen R, & Bech Risør M. The importance of contextualization. Anthropological reflections on descriptive analysis, its limitations and implications *Anthropology & Medicine* 2014 Vol. 21, Iss. 3.

²⁹ Nicholson BD, Mant D, Bankhead C. Can safety-netting improve cancer detection in patients with vague symptoms? *BMJ*, 355(i5515), 1–5.

³⁰ Fox RC. "Medical Uncertainty Revisited". In: Albrecht, GL, Fitzpatrick, R, Scrimshaw, SC. *The Handbook of Social Studies in Health and Medicine*. London: Sage Publications. 2000, pp. 409–427.

³¹ Malterud K, Guassora AD, Reventlow S, et al. Embracing uncertainty to advance diagnosis in general practice. *Br J Gen Pract* 2017; 67 (659): 244–245.

³² Jones R. After Achilles. *Br J Gen Pract* 2016; 66 (644): 115.

³³ Chapple A, & Ziebland S. Methodological and practical issues in cross-national qualitative research: Lessons from the literature and a comparative study of the experiences of people receiving a diagnosis of cancer. *Qualitative Health Research* 2017; 28(5): 789-799.

³⁴ Walshe K. International comparisons of the quality of health care: what do they tell us? *Quality and Safety in Health Care* 2003; 12:4-5.