

Improving our understanding of the experience of waiting for elective care.

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Introduction

According to NatCen's 33rd British Social Attitudes survey, the most frequently cited reason for dissatisfaction with the NHS in 2015 was waiting times (although these data referred to waiting for both GP and hospital appointments). In relation to the latter, between 2011 and 2018 there was an increase in numbers of patients waiting more than the target 18 weeks (from referral to treatment or 'RTT') to start hospital treatment (Care Quality Commission 2017/18), while waiting lists for elective care grew by one and a half million between March 2013 and November 2018 (House of Commons Public Accounts Committee, 2019). The Public Accounts Committee report's authors expressed concern that the national bodies responsible for setting and managing waiting times appeared to "lack curiosity regarding the impact of longer waiting times on patient outcomes and on patient harm".

Statistics published in 2020 (NHS Performance statistics, January 2020) show an increase in completed RTT pathways for planned care over the previous 12 months of 2.9 per cent. The numbers of those waiting less than 18 weeks increased but so did those waiting more than 18 weeks, resulting in a percentage fall in those waiting less than 18 weeks over the previous year. The Health Foundation reported data in 2019 demonstrating that people are being added to the elective waiting lists faster than the NHS can treat them, given the current "mismatch between the resources that have been put into the NHS and the populations' need for such services", especially those with more complex needs (adding that more than 14 million people now have more than two long-term conditions). Their analysis of the situation is mirrored by public perceptions: the results of the Department of Health's (2016) survey of Public Perceptions of the NHS and Social Care found that while over three-quarters (76 per cent) of the 1,025 respondents interviewed agreed that 'NHS waiting times for non-emergency treatment and care are too long', a 'lack of resources/investment' was the biggest perceived problem facing the Service.

"Waiting for surgery from the patient perspective is one area of inquiry that has received relatively little emphasis in the wait list literature" observed Carr et al in 2009 and this remains true today. What literature there is on how patients experience waiting for treatment/care in general (as opposed to that dealing specifically with waiting for elective care) identifies several broad issues as salient: patients' perceptions of the degree of negative impact their condition has on their lives; connected to this, the importance they attach to the urgency and timeliness of receiving the care they need (Eades and Alexander, 2019); the sense of a loss of control they experience associated with waiting; and the notion (and practice) of 'uncertainty management' (see Keeley et al, 2009). When people want to be proactive in taking charge of their own health, they are frustrated by long waiting times and the associated uncertainty exacerbates emotional distress, particularly if they feel they have been forgotten or 'abandoned' (Healthwatch Islington, 2018).

So, what does this review reveal about patients' lived experience of waiting for elective care and about how negative impacts might be ameliorated?

Four broad questions are addressed:

- What factors impact patients' experiences of waiting to see a specialist?
- What role do knowledge, information and communication play?
- What do we know about how patients are supported during waiting and how they experience support?
- Is there evidence of inequalities in waiting?

Review of Evidence from the Patient Experience Library evidence and the Care Opinion website

Certain categories of patients are excluded from this review, while other issues have been identified for inclusion where possible. Cancer patients and those awaiting care specifically for mental health issues are excluded since they are subject to separate targets. Particularly in the light of current concerns about mental health waiting times for young people, however, this may well be seen as a priority for future review/research.

Experiences arising from what might be termed 'ineffective pathway designs' are included, as is the issue of referrals that may be made conditional upon lifestyle changes such as weight loss or smoking cessation. How far the impacts of waiting may be exacerbated by inequalities or disadvantages is also addressed. These exclusions and inclusions aside, within the scope of this project, a full systematic review of literature on patient experiences of waiting for elective care was not feasible. The report is therefore based on a search and analysis of a sample of available evidence from the Patient Experience Library together with thematic analysis of a sample of 'patient stories' from the Care Opinion website. Search strategies are described below

Search of Patient Experience library

The Patient Experience Library contains over 60,000 publications on patient experience and involvement. These include surveys, studies and policy documents from sources including government bodies, patient voice organisations, health charities and academic institutions. It contains both formal literature and "grey literature", defined as publications that are ephemeral, poorly catalogued and hard to find. It does not contain documents that are held behind journal paywalls, or other literature that would normally be for sale from booksellers. Most of the content is from 2012 onwards.

An initial search covering all documents up to the 25 January 2020 and including both UK and international documents was carried out, using the following search terms: 18 week, appointments, elective care wait, waiting list, waiting times. This delivered 5,000 results.

These were refined in the following ways:

- for relevance, i.e. keeping only those featuring the search terms as a prominent part of their content (3,058 remaining);
- in order to eliminate any duplicates (1,599 remaining);
- to retain only those up to three years old (663 remaining); and
- a 'manual' sort to exclude those that were concerned primarily with mental health issues, urgent and emergency care, and primary care (42 remaining).

Confirming Carr et al's (2009) findings, the predominant focus of these was on documenting, analysing and reporting on *provider* perspectives and strategies in relation to the efficient management and improvement of waiting times for elective care. For example, a Royal College of General Practitioners report (Marshall et al, 2018) examined the effectiveness of 'referral management centres' aimed at reducing the length of time patients wait for elective care by improving the quality of referrals to specialists (and recommending that these be abolished in favour of 'referral support' systems in the form of facilitating closer communication between GPs and specialists). A total of 20 reports/articles were selected from the above search as being written from a patient perspective or as containing some (survey or 'qualitative') data on patients' experiences, in their own 'voices'.

In view of these relatively limited data and also in response to National Voice's interest in chronic conditions and socioeconomic variations, which weren't adequately represented in the initial search, a further search with these factors in mind was conducted using the terms 'patient experience' and 'wait/ing times/lists' on 'Google scholar'. This produced another ten reports and journal articles relevant to the brief and from citations in these, a further six sources were accessed. These have also been drawn upon in this review, therefore, despite the fact that some of them are international rather than England-specific and the fact that some of them pre-date current NHS Referral to Treatment¹ (RTT) policy and practice - on the grounds that the insights they offer are nevertheless applicable to the experiences of those on waiting lists for elective care. A more systematic and comprehensive search of the academic literature in the future may produce more qualitative research on this topic specifically from the patient perspective. The review of the literature presented here, however, is based on the 36 documents outlined above (see Bibliography).

Search of Care Opinion

An initial trawl was undertaken of stories dating between 2015 (when a review of the 18-week RTT measures was conducted by Sir Bruce Keogh, one of the aims of which was to ensure that the policy made sense to patients in practice²) and the present, using the search

¹ Patients referred for non-emergency consultant-led treatment are on 'RTT pathways'. An RTT pathway is the length of time that a patient waited from referral to start of treatment, or if they have not yet started treatment, the length of time that a patient has waited so far

² Norfolk and Norwich Hospitals NHS Foundation Trust provide a downloadable explanatory document for patients on the 18 week RTT Waiting Time, including the factors determining when the 'clock' starts and stops. <http://www.nnuh.nhs.uk/publication/rtt-18-weeks-what-does-this-mean-to-you-as-a-patient-v2-0/>

terms 'Wait/ing times' and 'elective surgery' plus the main surgical specialties (cardiothoracic, general, neurosurgery, oral and maxillofacial, trauma and orthopaedic, ENT, paediatric, plastic, urology and vascular). This produced 236 stories. Excluding stories about cancer patients, those concerned exclusively with mental health, paramedic and A&E stories and accounts of time spent in waiting rooms during hospital appointments reduced this set to 47 stories. An additional search was undertaken extending the period covered. This produced a further 251 stories of which 41 met the criteria. The analysis of the Care Opinion data is therefore based on a total of 88 stories.

Most of the documents from all of the above sources do not include explicit suggestions for what would improve patients' experiences of waiting for elective care. Where patients *do* make suggestions (as in The Patient and Client Council survey), these are included; otherwise, 'findings' about what would improve patients' experiences can be extrapolated from (often negative) experiences they report and/or from findings on related matters (e.g. the use of telephone- and video-assisted booking systems) that implicitly have implications for certain patient groups' experiences of waiting for elective care.

Summary Findings

The predominant focus of the literature on waiting for elective care is on documenting, analysing and reporting on *provider* perspectives and strategies in relation to the efficient management and improvement of waiting times.

The more limited literature *from a patient perspective* on the *lived experience* of waiting for elective care identifies a number of common themes (including pain, psychological distress, fears around deterioration in health, threats to employment and loss of income, and increasing lack of trust in care providers), contributing to an overwhelmingly negative picture of life described at its worst as being 'on hold' or in a 'no man's land', characterised by uncertainty and precarity in relation to family, work and social lives. For patients on waiting lists, a lack of *control* arising from the *uncertainties* involved in waiting and from fear of further deterioration and of loss of income/employment severely curtails the ability to 'get on with one's life' in a meaningful way and to plan effectively for the future. Care Opinion data provided plentiful illustrations of these themes.

The role of information and how and when it is communicated was shown to play an important role in patients' sense of control and their ability to manage uncertainty. This applied to:

- knowing what to expect in relation to length of waiting time
- what to expect at a scheduled appointment
- being given explanations that they understood at point of diagnosis
- knowing what to expect from proposed surgical procedures
- being given advice and information on health maintenance issues, exercise, use of walking aids, weight control and symptom control during the period of waiting
- knowing how to maintain connections with healthcare providers if/when questions emerged along the way or they needed to discuss ongoing health problems.

In many instances, the availability of such information was considered limited or completely absent. Patients in one study offered a number of information/communication-related suggestions for improving experiences of waiting for elective care:

- better communication would help in *managing patients' expectations*
- more accurate information is needed to enable patients to make *decisions on whether to pay privately*
- providing *status updates* could ease anxiety and reassure patients that they had not been forgotten
- the use of letters is outdated and more up-to-date processes to *support two-way communication* are needed

- patients would like more information on *what measures are being taken to manage waiting lists* and reduce their waiting times.

Care Opinion stories supported the picture painted in the literature, with some notable exceptions in the form of patients' appreciative accounts of being given helpful information. The overall implications of Care Opinion patients stories in relation to information and communication, however, are that (notwithstanding available resources) more work needs to be done around whose responsibility it is to keep patients informed about their progress on the waiting list (characterised as it often was by confusing stops, starts, 'diversions' and reversals); how lines of communication in both directions between health care providers and patients can be improved; and what formats in relation to the presentation/communication of information are effective in ensuring maximum accessibility, and in enabling patients better to manage their experience of waiting.

The literature shows a clear association between low levels of social support and high levels of fear and anxiety, but on the whole, the level and type of support patients received was down to luck, opportunity or persistence. Where a patient knew someone, who had undergone similar procedures to ones they were awaiting, they shared experiences and 'tips' on coping. Some patients expressed a readiness to make active efforts towards self-management and to engage in what has been referred to as 'pre-habilitation', but felt they lacked the necessary professional support to enable them to do so, and as a consequence they reported feeling 'in limbo' or in some cases, almost 'abandoned by the system'. Support while waiting for elective care was shown to be not simply an organisational matter or one to do with 'systems', but more a matter of taking a holistic, patient-centred, bio-psycho-social approach to thinking about what constitutes support and therefore what kind of provision would be most helpful.

Stories relating to the kinds of support needed, experienced or lacked did not feature significantly in the Care Opinion data analysed. In their place were the largest category of stories by far: graphic and powerful stories describing patients' journeys through the system, characterised by waiting/delays before the 'clock' officially starts; 'stop-starts' along the way; cancellations; changing goal posts and 'reversals', which patients simply did not understand. In some cases, this led to speculation about intentional 'tactical management' of waiting list/targets at the expense of patient care.

The literature revealed inequalities in experiences of waiting for elective care according to: nature of condition, regional variations, 'protected characteristics' of patients and socioeconomic factors. In one of the Care Opinion stories, the patient expressed appreciation for what effectively amounted to 'insider information' that allowed them to make progress along the list.

Analysis of the kind of qualitative data made available through Care Opinion, that privileges patients' own words and reflects their perspectives and priorities, bringing to life what is behind the 'findings' from official reports and academic research, confirms the gap between professional and 'lay' definitions of experiences of waiting for elective care that is not made explicit or articulated in the 'official' literature. To define or limit 'the patient experience of waiting' to that which happens during the period between referral and treatment represents a failure to understand how waiting for elective care is actually conceptualised and experienced by patients themselves. A (target) 18-week 'RTT' period is a 'technology', a

function of a 'supply-side' aim to measure, monitor and manage a 'waiting list'. While some patients may become familiar with and adopt some of the organisational language used by managers and other health professionals, it is evident that for them, their journey to treatment begins when they come to recognise what is happening to them/their bodies as 'symptoms'; if they decide that these symptoms warrant professional attention, this is the point from which they see themselves as embarking on a journey (often without a road map) towards treatment - as opposed to thinking of themselves in terms of being on a pathway.

Findings from the literature

What impacts patients' experience of waiting to see a specialist?

In a Canadian study of patient experiences of waiting for elective surgery, Carr et al (2009) observed that the literature on waiting times comes from two main sources: agency and government reports; and academic studies. In general, the focus of the former has been on gathering waiting times data in order to establish benchmarks and best practices, with policy recommendations based on these. The academic literature has centred more on the development of clinically derived priority criteria systems and their evaluation, with the aim of establishing standardised and reliable methods of determining fair and equitable access to health care services. These authors' review of the international English-language literature *from a patient perspective on the lived experience* of waiting for elective care identified a number of common themes contributing to an experience of life described as being in a 'no man's land' characterised by uncertainty and loss of dignity:

- Pain that restricted normal activities.
- (as a result of the above) Living an undignified and 'meaningless' life in which stigmatization, isolation and depression featured.
- A 'life on hold' experienced as a continuous struggle against what was seen by some as a 'faceless system'.
- (associated with the above) | The importance of establishing trusting relationships with care providers.
- (for some respondents, dependent on condition/awaited procedure) The ability to preserve a sense of living a full life in which pain, disability and uncertainty did not overwhelmingly impinge on everyday life.
- The significance of support from family and friends, varying from assistance with practical tasks to emotional encouragement.

Patients responding to the (2016) UK-based Patient Association study 'Feeling the Wait', exploring the impact on patients' lives of long waiting times for elective surgery, identified three key concerns:

- the significant psychological distress arising from the uncertainties of waiting and from cancellations; and
- the risks of deterioration in their health and the implications of this for their ability to prepare for change, for recovery times and for eventual outcomes (see also Lynch et al, 2008).

- A lack of transparency between Trusts and patients that left the onus on the latter to access information.

The issue of transparency also arose in Gill et al's (2017) study. These patients had no idea how decisions about precedence were made and wanted transparency around how surgeons triaged elective patients. Without knowledge or understanding, they were left to guess, based principally on media stories and other patients' experiences. They understood that they were in a queue but didn't know whether they moved up the list in order of presentation or if other factors determined their assigned waiting times. Although they realised that this would not solve the problems of individual harm from lengthy waiting, they believed that if they knew the system of triaging, they would have more confidence in its fairness.

Similar issues as those identified by the Patient Association emerged from the Northern Ireland Patient and Client Council's (2018) exploration of patients' 'lived experience' of waiting for healthcare. Based on a survey of 700 patients plus in-depth interviews with a small subsample, it confirmed fears around:

- a deterioration in (physical and mental) health;
- a worsening of pain;
- a negative impact on the quality of social lives and relationships with family members and carers; and
- a negative impact on financial wellbeing.

These issues are reported in particular by patients who are dealing with 'estimates' in relation to periods of waiting. In Gill et al's (2017) study, for example, patients reported the psychological impact of increased fear, apprehension, anxiety and depression as well as the practicalities of severe pain that affected their mobility; interfered with their day to day lives; or sometimes prevented them from going to work. It was the added burden of uncertainty that constituted a 'life on hold' characterised by a suspended ability to plan. Among working patients, even those who had been given a surgery date felt they had to 'ration' their sick days so that they didn't 'run out' before surgery, bringing either financial penalties or in fact putting their jobs at risk. From the point of referral to the waiting list onwards, participants in Parsons' (2009) study also expressed feelings of 'having no control over their lives' and 'putting their lives on hold':

"...I feel very tired, I want to sleep a lot...I feel very depressed...you get frustrated because you can't do things and actually I have got to say I just don't want to do anything...I can't be bothered and now that I know I am having the operation, I keep saying "I will leave that until I am better". I don't bother to do things any more..."
[participant 2]

Holidays, family visits and large purchases (e.g. buying a new car or home improvements) were postponed until after surgery, as 'being called for surgery' dominated their thoughts. At the same time, there was fear around being called in. Frustration, anxiety, depression,

lethargy, not knowing, shock, disbelief, worrying, feeling 'down' and tearful were all words they used to describe their experiences of waiting. Patients in Gill et al's (2017) study who *had* been given a surgery date reported that the one factor that helped them during the waiting period was that they knew it was finite and that they could fix their sights on an end to whatever they were experiencing during this time.

The main message from these reports is that for patients on waiting lists a lack of control arising from the uncertainties involved in waiting (see Charmaz, 1991) and from fear of further deterioration and of loss of income/employment severely curtails the ability to 'get on with one's life' in a meaningful way and to plan effectively for the future.

Communication/Information

What did patients say about communication with their healthcare providers during periods of waiting? The role of information and how and when it is communicated was shown to be significant in a number of studies. Knowing what to expect at a scheduled appointment was reported to be important, although it was often lacking. There were also reports of ineffective information-giving at consultations. A survey based on 10,000 responses from Neurology patients (Neurological Alliance, 2018/19) found that only 23 per cent of respondents reported being given an explanation that they understood when first given their diagnosis and 43 per cent were given no written information at this point. Perhaps unsurprisingly then, 30 per cent reported not feeling involved in making choices about their healthcare.

Patients in a study of a pain clinic (Healthwatch Lincolnshire) also reported that they didn't know what to expect at a first appointment, while the majority of respondents to the Northern Ireland survey by The Patient and Client Council (2018) said they would have liked to have received more information about what to expect from being on a waiting list. Nearly half of patients in this study felt it had not been made clear how long they personally would be expected to wait after receiving a first referral; and nearly 80 per cent also said they were not followed up while on the waiting list to determine whether they still needed an appointment (suggesting that they would have seen this as an improvement). Most of the patients in Gill et al's (2017) study also felt that they were waiting without any connectedness to a healthcare provider. They had not received adequate information initially and when questions later emerged, or they needed to discuss health problems, they were unsure who to call or how to get the information they needed. In Parsons' (2009) study of those living with severe osteoarthritis while waiting for surgery, patients also found that advice and information on the proposed surgical procedure, health maintenance issues, exercise, use of walking aids, weight control and symptom control were limited and in many instances were considered by the participants to be completely absent.

While being supportive of healthcare staff and appreciative of the care they did receive, patients in the Northern Ireland study made a number of information/communication-related suggestions for improving their experiences of waiting for elective care:

- better communication would help in managing patients' expectations

- more accurate information is needed to enable patients to make decisions on whether to pay privately
- providing status updates could ease anxiety and reassure patients that they had not been forgotten
- the use of letters is outdated and more up-to-date processes to support two-way communication are needed
- patients would like more information on what measures are being taken to manage waiting lists and reduce their waiting times.

Support

What do we know about how patients are supported during these anxious and challenging periods of waiting for elective care? Koivula et al's (2002) study of social support resources available for patients awaiting coronary artery bypass grafting certainly showed an association between low levels of social support and high levels of fear and anxiety, while other studies testify to a lack of support in practice. In Parsons' (2009) study of patients living with severe osteoarthritis, for example, there were no consistent healthcare professional-led sessions in place through which individuals could receive information, guidance, advice or support while waiting for elective surgery. Where a patient knew someone who had undergone similar procedures to ones they were awaiting, they shared experiences with each other and asked for 'tips' on coping, but on the whole, the level and type of support patients received was down to luck, opportunity or persistence.

There is also evidence to suggest that some waiting patients may be highly proactive in the face of the associated worries and frustrations - for example in Jowsey et al's (2016) study of patient strategies for coping with an absence of care coordination and continuity; and in Gill's (2016) study, which showed that most patients wanted provider guidance and some kind of ongoing connection that would enable them to keep as fit as possible. Some expressed a readiness to make active efforts towards self-management and to prepare more positively while waiting (what Gillis et al, 2016, refer to as 'pre-habilitation'), but felt they lacked access to the necessary information and guidance that would enable them to do so. They felt that they were responsible for working hard and 'advocating' for themselves just to get access to information and some kind of support; and as a consequence they reported feeling 'in limbo' or in some cases, almost 'abandoned by the system'.

Using a 'critical incident' technique, Ivarsson et al (2004) found that both 'internal' factors (e.g. changes in lifestyle; finding 'strength from within') and 'external' factors (the degree to which they were enabled to be active participants in their care management, the level of positive attention from friends, family, work colleagues and health professionals, the ability to maintain social networks), featured in experiences of support or its absence by patients awaiting cardiac surgery. Dissatisfactions were expressed in relation to organisational issues such as: lack of, conflicting or confusing communication, which impacted negatively both on patient-professional relations and on the patient's ability to prepare for surgery with confidence. The implications of this study's findings were that support while waiting for elective care is not simply an organisational matter or one to do with 'systems', but more a

matter of taking a holistic, patient-centred, bio-psycho-social approach to thinking about what constitutes support and therefore what kind of provision would be most helpful.

Inequality of access: factors influencing inequitable experiences of waiting

Nature of condition

There is some evidence to show that how waiting for elective care is experienced varies by condition. For example, in Carr et al's (2017) study, it was typically the case that participants awaiting orthopaedic surgery described pain as their principal restriction, while cardiac surgery participants were generally bothered by fatigue and role restriction. Further, both patients awaiting joint replacement surgery and those awaiting coronary artery bypass graft (CABG) surgery cited uncertainty about the length of time they'd have to wait as negatively impacting on their experience, but this was exacerbated for the CABG patients for whom "existential concerns about mortality risk" were emphasized.

In the UK, the (2018) All-Party Parliamentary Group report on Eye Health and Visual Impairment reported that just over half of the five hundred and fifty seven patients they surveyed had at least one appointment or treatment delayed, 20 per cent had experienced at least one appointment or treatment cancelled and 15 per cent reported experiencing both. Seventy seven per cent of patients reported that the delays/cancellations had caused them anxiety or stress, while 54 per cent reported a negative impact on their day to day life. They expressed concerns about long waiting times, problems securing appointments, a lack of continuity in their care and poor communication. Confirming the validity of the concerns patients have expressed about the potential negative impacts on their health of waiting in much of the evidence cited in relation to waiting in general, the All-Party Parliamentary Group report is evidence of the fact that delays and cancellations of time-critical appointments for patients suffering from certain conditions (in this case, poor eye health and visual impairment) can indeed result in life-changing deterioration (in this case, some patients suffering not only fear, loss of independence and impaired well-being, but "avoidable sight loss" as a consequence, p.3)

Regional variation

There are also marked regional variations. The Medical Technology Group (2017/18) found that nine out of the ten worst performing CCGs as measured against the 18-week RTT were in the south. In cardiology and cardiothoracic medicine, for example, figures ranged from 100 per cent of patients receiving treatment within 18 weeks in North Durham, to a failure to hit the target for even half its patients in Medway. Regional variations were also reported in relation to neurology patients, attributable, according to The Neurological Alliance (2019), to the lack of incentives for local areas because of the absence of any national prioritisation of neurology.

Protected characteristics

As appointment systems become increasingly technologised, the implications for the effective completion of pathways via these forms of service delivery for people with

'protected characteristics' also become apparent. A variety of barriers represented by telephone and video-enabled appointments were identified by Calderdale Healthwatch (2019) in relation to those who have: no or limited proficiency in the English language; sensory impairment; long-term conditions; physical or mobility impairment; learning disability; mental health conditions; autism; or who are older/frail. These forms of service delivery required technological skills which were currently lacking, as was the use of assistive technologies and support for carers, interpreters or others, which might have mitigated the barriers. Perceived additional cost implications of such support for the individual was also identified as a potential barrier.

In relation to those with autism, it is also possible to extrapolate from their experiences of access to autism services to how they might experience waiting for elective care. For some, even seeking a referral for assessment was problematic. Because there is a sizeable waiting list for this category of service user and high priority cases go to the top of the list, some people in a Calderdale study ended up waiting for years before getting an assessment (Healthwatch Calderdale, 2017). There was also a suggestion that these service users needed appropriate referrals for support with mental health and practical issues as soon as a right to referral to a consultant has been awarded, in order to prevent deterioration before a first appointment; and that more training for staff in how to manage patients with ASD is needed, including greater professional understanding of female-specific traits. Further research investigating the experiences of parents and carers of users of Autism Spectrum Disorder Services also identified waiting times for assessment and diagnosis as being too long, as well as identifying a need for more support for parents, carers and patients while patients were on the waiting list; and the need for written communications to be understandable for parents and carers, by for example including a 'lay person's summary' (Healthwatch Wakefield, 2017). It is not difficult to see that many of these findings could also be applied to waiting for elective care.

Socioeconomic factors

There is also evidence of socioeconomic inequalities in relation to waiting times. The Centre for Health Economics' (CHE, 2015) analysis, for example, reveals significant differences in waiting times between patients of different socioeconomic status (up to 35 per cent difference between the most and least deprived population quintiles). After controlling for selection due to patients' choice, the authors suggest a number of culturally-influenced mechanisms at play:

'Elbowing behaviour' by less deprived patients: "More socioeconomically advantaged patients are likely better endowed with information, networking skills, contacts and consciousness of their rights, enabling them to exercise more effective pressure to get prioritized for treatment (this specialist form of 'cultural capital' was referred to by some of the patients in the Gill et al 2017 study, who feared that they may be "getting bumped" by people who were "in the know")

Defensive medicine by medical staff and hospital management may imply that richer patients are riskier to disappoint if the health of the patient deteriorates while waiting, since they or their families are more likely to promote legal action

Unconscious bias occurring when doctors are better able to understand and interpret the health symptoms of patients who are closer to them in terms of socioeconomic status, or when for unconscious psycho-social reasons they may under-estimate the need in socially disadvantaged patients.

The main insight for policy arising from the CHE research is that “publicly-funded health systems are prone to substantial pro-rich inequalities in hospital waiting times, even in countries like England...” (p.25).

There was also evidence not only that some patients are aware of these inequities but that some more deprived sections of communities suffered greater disadvantage and distress than the general population. In the Patient and Client Council’s (2018) report on the lived experience of those waiting for healthcare, for example, participants highlighted the inequity in access to healthcare between those who are eligible to access private provision and those who are not; and research from Canada (Gill et al, 2017) suggests that the ability or otherwise to pay for care can apply to patients’ ability optimally to prepare for surgery by managing their own health while waiting (for example, when paying privately is the only way to access services like physiotherapy); while in York, changes to policy concerning thresholds for elective surgery in relation to obesity/weight reduction and smoking/cessation led the City Council and local MPs to raise concerns about the effects of these changes on the most deprived communities (Healthwatch York, 2019). Qualitative data from a small number of patients affected by these changes revealed that: coping with pain while waiting was exacerbated by their struggles to be active; financial and emotional distress was exacerbated by feelings that the changes were unfair and discriminatory; receiving confusing messages from healthcare providers was distressing for them, especially in relation to their BMI being cited as problematic very late in the period leading up to promised surgery; feelings that the goalposts had been moved since having successfully lost weight were distressing for them; and a lack of quality information and support around weight management (especially support that was geographically accessible) exacerbated the negative impact of waiting on this group of patients.

Findings from Care Opinion stories

What impacts patients' experience of waiting to see a specialist?

Illustrating findings from the literature review, a number of the Care Opinion stories confirmed that what impacted patients' experience of waiting included pain, the disruption to normal day to day life, the threat to employment and income, the inability to plan and prepare effectively, and the feeling of a life on hold before the possibility of getting back to normal. A typical example was a patient who was awaiting hernia surgery:

"I'm in a lot of discomfort and pain... I cannot work or live normally with this problem and it is likely that when I mention to my employer the date of the re-scheduled surgery they will no longer be willing to accommodate me... You prepare yourself both psychologically, and with life in general for your surgery and plan for things to get back to normal. It's awful to be told these plans were pointless when your surgery is re-scheduled but to find out you cannot begin your recovery for a further 3 months is devastating". [283297]

Communication/Information

It was clear from the literature review that patients experiencing waiting for elective care wanted information; that they found it helpful in ameliorating some of the 'downsides' of waiting when it was provided; but that they sometimes felt that the onus was on them to find it.

The small number of stories that included positive mention of receiving useful information confirm that it is very welcome when it does occur. For example, after a very lengthy process over a period of years and numerous consultations with different doctors, all to 'show her commitment' before being given approval for permanent laparoscopic sterilisation, the patient below comments on the way information enabled her to know what to expect when having the surgery:

"I had received information regarding the surgery weeks before so I knew what to expect." [558157]

But more typical were stories like the one below, recounting an absence of provision of information, leaving the patient to take the initiative to find it for themselves:

“I received no pre-operative information and was told that there was none available but five minutes on the internet put me in touch with a charity supporting my condition and the brain and spine foundation and a wealth of information and a helpline. Just a signpost to this information would have been helpful.” [Neurosurgery patient, 507147]

Even in accounts of patients taking the initiative to contact the service in search of information/explanations, negative experiences featured frequently. Examples included: calls and emails not being answered; telephone messages left not resulting in call-backs; and promises made to follow-up on a query not being fulfilled. Such frustrating experiences led one mother/carer of a patient awaiting a hip operation to engage in highly proactive information-seeking behaviour [402223]. Her story tells how she had researched patients' rights under the NHS Constitution and she described what she discovered as “very sobering”. She had learnt what her local hospital being ‘a major trauma centre’ meant in practice and discovered (and used!) the ‘Care Opinion’ platform. She had accessed NHS Choices statistics for Orthopaedics, discovered and read the National Health Executive’s online magazine, and contacted PALS.

As a result of these endeavours, she made a number of suggestions for improvements in relation to information and communication, aimed at: managing expectations of waiting time more effectively; positively managing your own health while waiting; and better signposting patients to a source of interactive contact with their healthcare providers. So, rather than “9/10 patients seen in up to 22 weeks” she felt it would be more useful to be given the range from shortest to longest waiting; that it would help if the Arthritis booklets in the hospital waiting area were amended from saying that a wait of 8-12 weeks is normal to something that gave a realistic idea of what your actual waiting time may be; that information on what you can usefully do while waiting would be valuable; and that the Care Opinion website should be more widely advertised in NHS facilities.

It is evident from the qualitative Care Opinion data that not all patients can command the necessary resources to enable them to search out the information they need. The evidence suggests that they don’t feel the onus should be on them to do so either. As a patient who chose the pseudonym ‘Mrs Very Angry’ to post her story about having now waited 6 months for gynaecological surgery which “Guidelines [insist] should be undertaken within 18 weeks of referral” commented, “It is shocking to the extreme that no-one from the hospital has contacted me personally in any of that time to tell me why” [220916].

It is also the case that not all patients have the ability to apply numerically-presented information effectively if/when they find it. For example, how easy is it for patients to answer the question “what does ‘9/10 patients seen in up to 22 weeks’ mean to me as a patient waiting for elective care here and now?” The implications of the Care Opinion stories in relation to information and communication are that (notwithstanding available resources) more work needs to be done around whose *responsibility* it is to keep patients informed about their progress on the waiting list (characterised as it often is by confusing

stops, starts, 'diversions' and reversals); how *lines of communication in both directions* between health care providers and patients can be improved; and what *formats* in relation to the presentation/communication of information are effective in ensuring maximum accessibility, and in enabling patients better to manage their experience of waiting.

Experiences of moving through the system: waiting/delays before 'clock' officially starts; 'stop-starts' along the way; cancellations; changing goal posts and 'reversals'

The literature review above gives some limited insights into what kinds of support were needed and available. This kind of 'data' was not a feature of the Care Opinion stories analysed. Featuring predominantly in its place were stories describing patients' progress through the system. Not surprisingly, patients who experienced a wait that went beyond what they felt was reasonable expressed their dissatisfaction, especially if this contradicted expectations that had been raised:

"Very long wait for gallbladder surgery – about 20 weeks, which was very disappointing since I had been assured waiting times were better at Stafford than Stoke" [365399]

Many of the patient stories on Care Opinion begin before getting a specialist referral (and some go beyond treatment per se to encompass post-operative care and recovery). For example, the story recorded by one patient who had undergone a hernia repair offers feedback on the 'whole journey':

"From my doctor's referral pre-op, consultation and surgery to my recovery at home the process was painless. And brought in considerably under the 18-week waiting period I had been told to expect" [408098]

An account of the more problematic experience of a parent of a 12-year old requiring a tooth extraction in hospital also began with a description of the difficult dental appointments that had resulted in the need for treatment under general anaesthetic that pre-dated the referral to a specialist, before continuing with:

"He has had 4 courses of antibiotics & on constant pain relief. After 5 months we finally had a Consultation who kindly approved the operation ... however they are now saying he may have to wait up to a year for this to Happen!!! He had already missed lots of time off school & I have lost work too & as a single Parent find it unbearable to keep dealing with ... it breaks my heart to see him regularly in pain & find this totally unacceptable. He is a child & looks to me to be his protector but I can't help him" [629130]

Patients understand that they cannot expect to be treated immediately but (again in line with findings from the literature on patients' lack of/understanding of how needs are prioritised and triaged and how the time they spend on a waiting list is determined), they often don't understand the delays along the way that result in a pattern of stops and starts; or why they can't seem to get any explanations or advice from consultants whose care they are supposed to be 'under':

"[The consultant] said there was a good 6 month waiting time and if things get worse to go back to my GP...Things have been steady getting worse so I contacted the urology department at the end of January to try to see what was going on, I was then told there is a 12 month waiting list. I went to see my gp in March because of the pain getting much worse. It took 3 weeks to get some kind of response from the hospital which was that they are busy so please just wait. I can't get to talk to the consultant. Any questions about waiting times are either ignored or I just get told the operating theatres are being renovated so everyone is waiting longer. I'm supposed to be under the care of a consultant that I can't get to talk to to ask questions about my treatment." [Urology patient, 357829]

"My daughter has been crippled by 9 months of waiting for a diagnosis...(involving A&E visit, emergency admissions and various consultations with specialists across different departments). She has lost over 2 stones ... and feels her life has come to an end. What we don't understand is the lengthy times between seeing anyone. It appears that you have to wait up to 2 months between moving on to another consultants department. She has to wait 8-10 weeks to get CT scan results and 2 months to see a pain management team." [296946]

The extract above is from one of a number of stories describing 'stop-starts' in patients' progress from referral to treatment, the reasons for which were unclear to them and which were experienced as hugely frustrating. It took one patient nearly 6 months from acquiring a knee injury to be "put forward" for arthroscopy with chondroplasty and a further 5 months till they had what proved to be unsuccessful surgery. The medical reason for the unsuccessful surgery was discovered but the patient was then told to wait for another 2 months to be 'reviewed' and the reason for this was not understood: "I don't know what they expect to happen in the 2 months... here I am a year after the initial injury and still in the same situation ... I am still in more or less constant pain, it is affecting my work and social life ..." In the end, this patient got so frustrated that they got a GP referral to another hospital, where their care at the point of writing was progressing more quickly. "It feels like they actually care about trying to help you" they observed of the second hospital [521358].

When patients don't understand the reasons for such delays or when all their efforts on their own behalf are thwarted, there can be a tendency to suspect tactical factors at play. One patient who had been waiting 32 weeks to be put on the list for spine surgery suspected that the stops and starts they'd experienced were a function of organisational manipulation:

"I feel to keep numbers down, people are sent back and forth to other services, sometimes unnecessarily to turn the clock on and off to make it look like people aren't waiting as long as they actually are." [339136]

Another patient awaiting fertility investigation, who had been waiting 6 months from referral said that it "just felt like they were stringing things out to see if I'd get pregnant in the meantime" [271221]. And a third who had thought they were on a waiting list for ear

surgery and had waited fourteen months, punctuated by various out-patient appointments the necessity for which they didn't always accept, before discovering that they hadn't been put on the list in the first place, commented:

"I think they knew exactly what they were doing. It seems to me that putting patients on a waiting list does not depend on the clinical need nowadays, as the NHS founding principle suggests. It is managing the waiting list, or making it look good on the statistics". [91000]

And after a catalogue of set-backs, being given conflicting information, and a lack of progress on the list, a patient who works in the NHS suspected that having already breached a target time before suffering a cancellation, they were "now likely to be overlooked for dates as I was already a statistic and the emphasis would be on those who could be kept within their 18 week RTT time". The "happy ending" that followed, albeit after 25 weeks' wait, finally came with the help of some 'insider information' on how 'the system' works:

"I would like to thank the waiting list office ladies who were really kind and tried to help me. They were the ones who advised me when to ring for the best opportunity of getting listed and it worked" [230275]

The stories of those without the advantage of such help suggested that a lack of understanding of what determines one's progress along the waiting time-line can lead to questions being raised as to who 'the system' actually serves in practice, as illustrated by another story from a patient seeking a referral for a replacement hearing aid, who on being told that the GP couldn't oblige "because of their pathway", commented:

"The pathway may suit the surgery but it doesn't suit me" [440069].

Cancellations in particular were experienced as exacerbating even further the negative impacts of waiting:

In mid-August I was discharged from fracture clinic who referred me to see surgeons for acl (stet) reconstruction. was put on waiting list. I call the secretary of that surgeon in oct 2019 to be told they had not seen the referral that was sent. I had to inform them that the referral was on the care portal. I was then told I would have a appointment towards the end of oct 2019. I was informed the day before the appointment that it was cancelled as surgeon will not be back until Dec..." [708331]

"This will now be the 5th cancellation... The whole situation has left me down and low. I have been off work sick with stress of everything... I have asked them to move it to another hospital, they just refuse to look at this option. I don't know who else to speak to. I have contacted the CCG, nothing doing there..." [37546]

“The first (appointment following attendance at a hand clinic) was scheduled in January but was cancelled. The next one wasn’t due for another 11 weeks (late July). The day before the appointment, somebody called and said this one had to be cancelled because there wasn’t going to be any available hand consultants to see me that day!... Nobody sent me another apt, so I had to call and request one 2 weeks later. Then I was told the earliest I could be seen was 2nd August. I called my consultants secretary ... as I am now in terrible hand pain. She managed to arrange one for mid July but this still means I have been waiting for 6 months with cancellations and waiting times getting longer and longer...” [522534]

This patient then contacted a manager and was told that their surgeon would be changed and a new appointment sent, but they were still waiting 19 weeks after their accident. “This service has not kept me up to date” they commented, while reporting a painful leg that is no longer reliably weight-bearing.

In another case, a patient who had been referred for a cataract operation suffered a ‘reversal’ at the point they finally got to see the surgeon:

“Surgeon then declined to do the operation and was sarcastic about opticians, although it was one of their colleagues who had agreed I should have the operation.” [534974]

And another whose consultation with the specialist confirmed that they would be given knee replacement surgery, and who made enquiries 3 months later about where they were in the queue, was told at this point that there was no funding for this operation. Their GP had apparently known this and had assumed that the patient did too. “I would very much like to know by whom and when this decision was made and why no-one thought that I needed to know” their story concluded [399518].

It was when patients found ‘the system’ completely unresponsive, however, that they expressed feelings of being abandoned and at a loss, as the patient below reported:

“The booking forms came through within 2 weeks, to go online and book an appointment, logged on to book to be told there were no appointments available and that someone would contact me This was the start of August. At the end of August I received a letter saying I was on a waiting list for an appointment. It is now the start of November and I still have no appointment and concerns for my sight in my eye! I have emailed the booking department with no reply. I’m lost with what to do, with no help from my GP, who said she’d had to wait a long time as well (no help to me)”. [423004]

Conclusions

“I am now losing hope that I will ever get my life back” [236586]

This review of literature on experiences of waiting for elective care is by no means exhaustive but what it shows is a bias towards a ‘provider’ perspective in research to date and, given the gap between this and patient perspectives revealed by the analysis of the Care Opinion patient stories, a need for further research on patients’ experiences of awaiting elective care that incorporates patients’ own voices. One study (Johnson et al, 2014) using pre- and post-operative in-depth interviews with patients waiting for hip replacement stood out as the exception here, in what it revealed about the complex, multi-dimensional, subjective nature of the experience and conceptualisation of time in the lead up to surgery. Patients’ experiences did not reflect “the linear, monochronic conceptualisation of time embedded in the healthcare system, with its policy focused on targets and measurement of (segments of) time once a patient is scheduled for surgery against the external ticking of the (medical) clock” (p132).

Analysis of the kind of qualitative data made available through Care Opinion, that privileges patients’ own words and reflects their perspectives and priorities, bringing to life what is behind the ‘findings’ from official reports and academic research, confirms the gap between professional and ‘lay’ definitions of experiences of waiting for elective care that is not made explicit or articulated in the ‘official’ literature (Johnson et al excepted). To define or limit ‘the patient experience of waiting’ to that which happens during the period between referral and treatment represents a failure to understand how waiting for elective care is actually conceptualised and experienced by patients themselves. A (target) 18-week ‘RTT’ period is a ‘technology’, a function of a ‘supply-side’ aim to measure, monitor and manage a ‘waiting list’. While some patients may become familiar with and adopt some of the organisational language used by managers and other health professionals, it is evident that for them, their journey to treatment begins when they come to recognise what is happening to them/their bodies as ‘symptoms’; if they decide that these symptoms warrant professional attention, this is the point from which they see themselves as embarking on a

journey (often without a road map) towards treatment - as opposed to thinking of themselves in terms of being on a pathway.

Where patients' own voices are present, it is clear that more could be done to alleviate the negative impacts of the fears and uncertainties inherent in waiting for treatment, in terms of the provision of information at various points in the patients' journeys (without their having to extract it from what sometimes feels to them like a system designed to withhold it) and of keeping lines of communication open between patients and health care providers in order to: help patients understand the criteria by which decisions are made; provide reassurance that they have not been forgotten or abandoned; and allay suspicions of more tactical motivations at play that result in diversions and delays.

Inequalities in access to progress along waiting time lines are not going to be readily overcome but where these are due to 'cultural' factors, it is the responsibility of professionals to be aware of how 'protected characteristics' (for example) might impact a patients' ability to cope with delays to treatment; and to be 'reflexive' around issues of greater or lesser alignment between their own and patients' socioeconomic status and how this might affect decisions around need. Professionals' adoption and maintenance of a bio-psycho-social model of what constitutes support for all patients, despite the pressures health care providers are under to meet external targets on waiting times, might enable patients to feel they are being cared for during what is inevitably a difficult time for them.

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