



Understanding Older People's Experiences of Oral Health Care

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Learning Outcomes

- To understand person-centredness and the value in focussing on people in a holistic manner.
- To appreciate patients' experiences of dental care and understand how patients may experience care differently from that which care providers may anticipate.
- To gain insight into how understanding patients' experience can support the improvement of person-centred care for individuals as well as supporting the advancement of healthcare services.

Introduction

Older patients bring a lifetime of experience with them each time they access health-care services. Each person is an individual whose life experiences shape their views of health, illness, and health services. As well as medical, psychological, and social

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influences, these experiences influence patients' needs and expectations of health-care, including dental care, in various ways. Older people do not appear *de novo*; they have been shaped by their journey through the course of life, having been exposed to the effects of age, the impact of many events occurring at different times, and effects that are specific to their generation [1]. As for all patient groups, dental care should be person-centred, meaning it should focus on the needs of the whole person, rather than simply the medical or technical aspects of care [2].

Though clinical guidelines and recommendations exist for dental care, patient autonomy is critical, and patients' preferences may not align with what guidelines recommend. On this basis, dentists should support patients to express their views and priorities in the dental setting in order to guide the care they receive. Good communication between patient and members of the dental team is vital to achieve good outcomes, yet to do this, clinicians must establish a connection with patients to understand their beliefs, attitudes, and preferences [3]. Such connections need to be made throughout the dental journey from initial contact, access to the surgery, reception, consultation, and treatment. Patient stories, or stories told by patients' representatives, are a valuable tool and can provide valuable insights to inform improvements in care in a manner that might not occur through discussions in clinical encounters. This chapter sets out four very different patient stories illustrating individuals' perspectives about care and highlights how individualised and person-centred care can be provided.

The Personal Impact of Illness

Though most people experience episodes of acute illness that resolve (sometimes through medical or surgical intervention), chronic illness and multimorbidity (the existence of two or more chronic conditions) becomes increasingly prevalent with increasing age [4]. Chronic conditions can drastically affect individuals and typically impact many aspects of a person's daily life. Most people try to keep illness at the margins of their lives for as long as possible, yet there can be a limit to how long such 'normal' living can be maintained. The progression of chronic disease is not necessarily linear, meaning chronic illness can be experienced as an interruption to people's lives, as an intrusion, and even as an immersion as a disease progresses and becomes all-encompassing [5]. Figure 3.1 illustrates a mobility scooter which supports someone to function despite a chronic illness; using such a device is an example of an attempt to maintain normality yet initial use of such a device may certainly reflect an interruption to 'normal' living. Living with serious illnesses can catapult people into a different reality where their previous life and abilities may be increasingly compromised. Within this altered life, people will typically have good days and bad days concerning their illness. Health professionals need to consider the individual and their experience of any chronic illnesses alongside their dental needs in order to provide holistic healthcare [6].

As well as affecting general health, chronic illnesses can significantly affect oral health. Either the conditions *per se* or their treatment can directly impact oral health.

The complexity of living with a chronic condition can relegate oral care and regular dental attendance to a lower level of priority and precede a potential proliferation of oral diseases. Pain, infection, or tooth loss are common in older age groups and can be highly impactful, including in later life [7–9]. Rousseau et al. [10] found that tooth loss was relatively insignificant for some people, yet it was devastating and disruptive for others [11]. The individual shown in Fig. 3.2 has a beaming smile, yet tooth loss could lead to alteration in both his self-perception and in how others may perceive him. Such impacts must be understood on a person-by-person basis, as other patients may not share such concerns.

Dental teams need to consider the impact of chronic illness in older people and be aware of the possibility that a person's attitude towards dental care may change over time. The potential for avoiding dentistry may also be a factor in this age group for many reasons such as anxiety, having more significant priorities, or financial concerns. Historically, tooth loss was more acceptable, and people in their later life had fewer dental needs. Increasingly, people are striving to retain teeth, and many recognise that dental health is an important part of keeping well [12]. Tooth retention into old age should have a huge advantage in terms of healthy ageing. However,

Fig. 3.1 A mobility aid may be required as illnesses progress. These aids can help people maintain their independence yet people have to adapt to their illnesses and devices to support them living with illness. (Image Courtesy of Centre for Ageing Better)



Fig. 3.2 This individual with a visible dentition when smiling may find loss of teeth a drastic alteration to his usual state; however other patients may not find tooth loss to be so problematic



poor oral health and tooth loss later on in life can have the opposite effect, being disabling, costly, and adversely affecting the quality of life [13, 14].

Person-Centredness

Person-centred medicine has developed as a concept over the past 50 years [15–18]. Person-centred care is defined as care in which “individuals’ values and preferences are elicited and once expressed, guide all aspects of their health care, supporting their realistic health and life goals” [19]. True person-centredness extends beyond medical considerations and considers wider aspects as the person such as who the person is and their interests (examples shown in Fig. 3.3). The emergence of person-centredness reflects the perceived shortcomings of the disease-oriented or illness-oriented models of care [5], which reduce individuals to a set of signs and symptoms and healthcare professionals to a more technical role. Boggatz [20] suggests that a person-centred approach is based on the conviction that people have central concerns according to which they shape their lives; therefore, person-centred care is the required response to an older person’s quest for quality of life.

Dentistry lags behind other health professions in progress towards person-centredness and remains deeply anchored in a biomedical vision [21]. In a biomedical approach, there is little interest in understanding patients’ lives and preferences and consequently minimal openness to shared decision-making about appropriate care [21]. In a systematic review of the dental literature, Scambler et al. [22] conclude that the concept of person-centred care is neither clearly understood nor empirically and systematically assessed in dental settings, particularly in general dental practice. While most authors suggest that person-centred care is about

Fig. 3.3 People seeking dental care may well have multiple interests and areas of their lives that affect their approach to and desired outcomes from dental treatment. (Credit: Chris Redford)



delivering humane care, involving good communication and shared decision-making, there is little published work that assesses these concepts empirically or relates them to practical outcomes in dental settings. The delivery of person-centred care is an essential aspect of providing quality dentistry. Failure to provide this approach to care compromises the engagement of patients as individuals and potentially diminishes the opportunity to understand how best to support each person in preventing dental disease and improving oral health [23].

Understanding Patients' Experiences

A basic understanding of patients' experience comes from the early part of a clinical consultation. The history-taking process allows a patient to explain the background of their symptoms and what they hope to gain from seeking healthcare. Numerous psychological and sociological factors impact how much information patients may actually share when attending an appointment [24]. Furthermore, the purpose of information sharing is to support a diagnosis, and move towards collaborative decision-making. It is paramount that dentists seek the patient's worldview. A more thorough and in-depth understanding can become especially appropriate when the approach to care provision is associated with increasing surgical, medical, or financial complexity. There is an even greater need to ensure patients are adequately informed to proceed with and consent to any proposed treatment in such instances [25]. The process of shared decision-making is described in depth in Chap. 11; a core element of this is the clinician's responsibility to seek information from the patient and for the patient to share this [26]. While the dentist has expertise in dentistry, the patient is the expert on their health, including their oral health, and their circumstances and preferences [26, 27]. Both areas of knowledge are essential to support care delivery.

Where patients can openly share their experiences, such as in social settings on blogs, social media or interviews, the constraints of the clinical environment are absent, and a patient may express their viewpoints both in more depth and with more openness. The words of a patient to a friend, carer, or relative before or after a consultation are likely to really display their hopes and expectations and, later, reflections on the experience of dental care itself. Whilst history-taking serves a crucial purpose, understanding patients' experiences beyond the dental setting—either individually or collectively—can expose a clinical team to a different perspective or allow a critical analysis of the appropriateness of their consultation style and approach to care delivery.

Despite the growing emphasis on patients' experiences, exposure to patients' viewpoints outside of a clinic may not be encountered in the ordinary course of events. Professional seminars or workshops typically present clinical speakers, and some such events do invite patients to contribute. Such events can illuminate the reality in which patients live. For example, the British Society of Gerodontology invited a person living with dementia to speak at their 2019 Winter Conference. The individual had an open session and was allocated around half an hour to do so. They

were able to share whatever they felt important without any consideration of their dental status. The words presented were generally seen as a highlight of the event and provided a great deal of food for thought. Similarly, HANCC (The Northern Head and Neck Cancer Charity) have invited multiple patients to share their views with the dental profession. The stories shared presented patients' knowledge and lived experience in a detailed manner, in sharp contrast to a snapshot that may result from a simple clinical encounter. Of course, it is not feasible to gain this level of insight into each patient's life yet taking a step back to appreciate the role we play in patients' wider lives can help professionals fulfil their professional duty to their patients.

Examples of Patient's Stories

Here we present four stories from patients or family members describing accessing and experiencing dental care in older age. Each illuminates different challenges that have arisen at a later age and their impact on successful dental care provision. These are presented in the patient's or family member's own words and have only been modified to ensure anonymity. These stories demonstrate what may happen for patients before, during and after dental care. Merely reading through these stories may provide a reader with a new perspective. The stories could, in theory, be analysed by formal methods, and they do bear a resemblance to transcripts that arise from planned research interviews. However, this is not the intended purpose of the stories here. They are presented so the patient voice is embraced to reflect how dental care may fit into people's lives and how receiving dental care across the life course can be both disruptive and highly beneficial.

William's Story

The perspective of a 93-year-old who still lives independently:

"I love being old. I think it's because I never thought I'd make it this far! I was diagnosed with cancer in 1997, and they told me I'd be dead in 6 months, but I sure showed them! I think most people would be angry if they'd prepared to die and then lived, but I've had a great time. I've no family, so I spend my days dancing. I've even been on stage, right up until COVID! It's great to live without worrying about getting ill with age, as I'm already old and I don't feel too ill. I outlived my ex-wife and that makes me smile.

When I think about teeth, I think I've been lucky. My part top denture sits in OK and gives me my big wide grin. I wear it at home even though I live alone. It just makes me feel better to smile. These top front teeth are all-porcelain as I fell down at some point...I must've been 50 or so. It was fine, but about 5 years ago, it all got really sore. I had to go through some horrible procedure to take the bottom of the tooth out and leave the top bit in because it's attached to the other teeth—that was horrible, but I got over it. It's been fine since, but earlier this year, my regular dentist said it needed sorting out and sent me to a specialist. I was convinced the specialist would tell me I needed them all out, but they said I didn't have to if I didn't

want to! I was so relieved! I know they're not great and a bit loose, but I really didn't want some bigger false ones. I can eat whatever I want now, and I can cope with a bit of a niggle from time to time. I really don't want to keep coming and paying for things to get sorted unless it's the only option. How can I keep going to my dance group if I have to waste time at the dentist?"

This story illustrates an individual with a very positive attitude to life, with a clear idea of his priorities. A key point of William's story is how much of a positive impact a denture has on his daily life. It is also important to note that he reports a positive outcome from being given a choice about his care; this demonstrates the need to understand patients' preferences and make shared decisions about what dental care may be most suitable for them.

Holly's Story

The experience of a 90-year-old man who entered a residential care setting after an acute illness, as told by his daughter:

"My Dad was 89 this year. He a history of chronic heart failure, COPD, atrial fibrillation, prostate cancer and macular degeneration. It was one thing after another as the years have gone by, but he stayed positive. Until 2019 he lived with my Mum and was completely independent. He was still driving and spent many hours on his computer. He was phenomenally organised and managed the household finances with precision. He used to be a bank manager, so he was always on the ball with the banking. He had always gone for check-ups and whatever care he was told was needed. He had lost a few teeth but still managed to eat well. He had some gold fillings and crowns and generally did whatever the dentist suggested.

Dad saw the hygienist regularly when he saw the dentist, but over the last 2–3 years, he had become anxious about seeing the hygienist as he felt he was going to choke and struggled to breathe due to his COPD and the water in his mouth. Following discussion with his dentist, and in view of his teeth being in good condition for a man of his age, it was agreed that he could stop these visits and just see the dentist. In April 2019, Dad became acutely unwell and was admitted with urosepsis and an exacerbation of his heart failure, with his heart now only functioning at 25%. After a few days of IV antibiotics, which proved to be ineffective, he was deemed to have a poor prognosis of 6 weeks. Due to his high level of nursing needs, he was moved to a nursing home. He was drowsy, confused, not eating, and doubly incontinent. This was a massive change for such a proud and independent man and very distressing for all of the family.

In spite of all his problems, Dad rallied round. He struggled to eat as he had problems with oral thrush, which altered his taste. His previously good appetite, with a particular love of all things sweet, was reduced to nothing but glasses of milk. Family and care staff all tried to tempt him to eat, but each time he tried something, it didn't taste as it should. He had three treatments for oral thrush, but nothing solved his problem with taste.

The Nursing Home staff referred Dad to the Community Dentist for their opinion and advice. The dentist found his teeth to be in excellent condition for a man of his age. He explained that he hated to miss a dentist appointment and followed a good

dental routine at home (though this was sadly missing whilst he was so poorly in hospital). As the dentist could find no cause of his taste problems, she arranged to see him in 6 months. My mum was visiting each day and helped him to clean his teeth by switching his toothbrush on for him. Though he gets fatigued very quickly, Dad continued to cope well in the same nursing home with good support from the staff for his care needs. He struggled to eat still due to the taste problem and having difficulty in chewing. His physical and mental health has deteriorated and he has lost a lot of weight throughout 2020. Dad died at the end of 2020 after a rapidly becoming more unwell and being admitted to hospital. We weren't aware of any oral or dental issues at this point and it certainly wasn't the priority when Dad was so unwell".

This story again illustrates an individual with a very positive attitude but whose severe illness has potentially compromised his oral health care. It is worth noting that Holly says her father always complied with recommendations from a dentist, demonstrating a potential desire to trust a professional instead of contributing to a shared decision-making process. This story also shows how a person's circumstances change over time, and how they receive dental care may also have to change. Holly's father had previously sought regular dental care in general practice, even when co-morbidities impacted his daily living. Once in a care setting, it was no longer feasible to receive this same dental care. A specialist team became involved when necessary; such a change demonstrates a transition from routine preventative care to more symptom-driven interventions.

Mandy's Story

The perspective of a person living with dementia, in her own words:

"I was diagnosed with Young-onset dementia 6 years ago at the age of 58. That age may not immediately fit with your stereotypical image of someone with dementia. So, contrary to popular belief, dementia isn't age-related. When people think of dementia, they think only of the end stages. However, it has to have a beginning and a middle well before the end stage arrives and some abilities stay intact far longer than others. We have an invisible disability that may be far from obvious when we attend our dental surgery. So it's crucial to ask for our history, but more important to look for the clues as not everyone has or wants a diagnosis of dementia, such is the stigma associated with dementia.

When I lived in Hampshire, soon after diagnosis, I told my dental surgery, and we agreed on a plan on what would work and what wouldn't. They even asked around colleagues to see what others were doing. They were terrific and worked with me. Then I had to move, and I had a very different dental experience—no two-way conversation on what might help, no smiley faces. I had to leave as they simply didn't understand. I have now found another fantastic dentist.

So, what made the difference between good and bad? First of all, I have trouble with the telephone—I never answer the phone now as people are often impatient at the other end and because they can't see me thinking, they interrupt which means I forget what they asked in the first place and get in a muddle. How many NHS Services, including dentists, rely on you contacting them by phone? I can do face

time because I can see the people and they can see me, but not the telephone. I can do text because I can still type and can take my time. I can type as though dementia never entered my life, as that part of my brain thankfully hasn't been affected yet. I can type quicker than I can think and speak the words. So the person you imagine me to be from reading this might not be the person you're expecting if you met me in person.

So with the first two dentists, sadly, I had to get my daughters to ring up for an appointment. With my GP I can book an appointment online. Why not with the dentist? Because I can no longer speak on the phone, they did agree they would send me text reminders. They reminded me the week before, the day before and the morning before as we forget in an instant. I've convinced my current dentist to allow me to email them. It means I don't have to wait for my daughters to be free, and it means I still feel in control of my own life.

The waiting room always had the local radio on, but when I enter, they either turn it off or turn it down, as I can't cope with sensory overload. Being spoken to and having the noise of a radio in the background simply merge together so I can't hear either. Being clear on where I should sit is so important. We need clear, simple instructions. My previous dentist's receptionist would say, "Take a seat in the waiting room upstairs", but without telling me where the door for 'upstairs' was. If a door is closed, I often can't see it. It's important to remember that dementia is not just about memory as so many of our other senses are affected as well. Vision is often one. Our eyes see, but our brain doesn't always interpret the information correctly.

So what can dentists do to help us? Well, I've never been to a dentist yet with good signage. If we can't see where we're supposed to go, we get anxious, and we'll walk into the wrong room. We even get lost. It starts before we even enter the building with a friendly welcome sign on a coloured door we can see with a simple handle. Then reception. The dentist can be a scary place with or without dementia. With dementia, it can be a bigger nightmare. A smiley welcoming face goes a long way to allay fears and calm people down. It's incredible how many people forget the value of a simple smile and welcome. Give us time to talk. Don't be afraid of silence. It often means we're thinking. If you ask another question, we forget the first, so we will just get more confused, more anxious. Don't bombard us with questions, don't rush us. Remember, our brains aren't capable of speed. It takes us forever sometimes just to remember how to walk in a straight line. And please don't say, "remember when you came last time"...because we more than likely won't, and it can make us feel stupid and confused.

Please don't chat with colleagues when you're treating us—the noise of the drill is disturbing enough. To have chatter or music as well as the drills can be simply overwhelming for many. For some, it might be OK. Just ask us. Most of all, be calm, don't rush and give us time. As for cleaning my teeth, well sadly, I imagine some days I clean them more than twice and others may be less, as we simply forget or believe we've done something when we haven't. That's why I visit my dentist every 3 months to get them cleaned and checked.

Finally, we are always saying that if you get it right for people with dementia, you will be helping so many others."

This story illustrates that patients with dementia may have an excellent understanding of their condition. They may be able to advise professionals on their attitudes and what interventions may greatly improve their dental care experience. It also shows how a negative experience led to seeking alternative care. The need to find an alternative dental team could be avoided if such teams aimed to support access for people with cognitive impairment or other conditions that can arise in later life.

Mary's Story

A relative's experience of the absence of dental care in a care facility:

"My first experiences, some 10 years ago, of attempting to access dental care for a relative living in a care facility for people with dementia, were not good. My relative had been living at home with increasing cognitive decline for some years but had been able to cope well with visits to the dentist and necessary treatment, including extraction of a number of teeth. Once his cognitive decline reached the point where he required admission to a care facility, I was anxious that his physical health needs and personal care needs would continue to be met and that this should include regular dental assessment.

The facility manager initially told me that no dental service was available for patients. There had been a visiting dentist in the past, but that individual had stopped coming and had not been replaced. No attempt had been made to identify a new dentist. I was shocked and surprised to be told this, not just that there was no access to dental services, but that the care facility apparently thought that this was not a matter that needed to be addressed. My reaction was emotional rather than intellectual: I felt that surely it was bad enough to lose one's memory and sense of understanding of the world, to be confused and frightened by one's surroundings, to lose one's home and to be placed amongst strangers, some of whom displayed aggressive behaviour—and then not to have access to aspects of health care which the rest of us take for granted.

At this time, I had been an NHS employee for almost 30 years and consequently had a good understanding of how things worked. I made two telephone calls: one to the local Community Dental Service and one to the local branch of the Alzheimer's Society to ask if they had a list of dentists who would attend a patient in a care facility. Both calls had an immediate and positive outcome. The Community Dental Service said they would be happy to attend, they would place my relative on the waiting list for a visit, they would be happy to receive referrals to see other patients at the care facility while they were there, and they would be happy, if asked, to send one of their staff to the care facility to train the care staff in carrying out oral hygiene in patients with dementia. The Alzheimer's Society duly provided a list of dentists in NHS and in private practice. I shared all of this intelligence with the care facility and dental services re-commenced.

The next issue was persuading my relative to co-operate and to open his mouth for the dentist to assess him. This proved to be very difficult, and none of the professionals or care staff concerned was able to think of a way around the problem. My relative at that time had been prescribed a benzodiazepine to calm his restless behaviour, and I suggested that the timing of administration of this drug could be coordinated with the timing of the dentist's visit. However, this proved a step too far in agreeing to arrangements across staffing shifts and handovers, and we had to give up the idea of dental assessment altogether. If a dental emergency had occurred, it would have been treated as a medical emergency.

This problem reminded me of my relative's earlier experience in a linked care facility for patients with dementia where patients were not given their glasses to wear. This was because patients were constantly taking them off and losing them, and it then became a challenge for staff to reconcile the correct spectacles with the correct patient. So the spectacles were collected and placed in a biscuit tin—to be sent in due course those in need! Hence in this instance, in addition to the very significant cognitive and sensory losses experienced by the patients, they were not enabled to see clearly either. These examples illustrate an absence of care for patients as individuals, where convenience for staff was seen as more important than maintaining this sense of self”.

This story illustrates a management failure in a care facility where dental care was simply not provided, despite being readily available on request. It demonstrates how advocacy can be required for those who may not be able to proactively seek their own care and how a relative could support service improvement in a residential care setting and establish a link with a professional dental service.

Using Patients' Experience to Support Service Improvement

In England, three key domains contribute to quality healthcare: patient safety, clinical effectiveness, and patient experiences [28]. Services should examine these areas using appropriate measures to drive quality improvement. Historically, there was a focus on outcomes that professionals deemed important; this only allowed determination of quality or improvement to be viewed from a professional perspective, not from those actually using healthcare services [29]. If person-centred care is to be provided, it is essential to use person-centric quality measures.

In oral healthcare, as with wider healthcare service, patients and their family or carers may have significantly different views about what is important to achieve “good” or quality healthcare and what is seen as “satisfactory” in terms of outcomes from care. In addition, regardless of the outcome of care, a person's experiences may have been positive or negative. For example, though a patient may have satisfactory complete dentures, a reasonable clinical outcome, they may have been treated rudely or without compassion in the process of dental extractions and denture constructive. Experience and outcomes of care are different aspects of quality that require separate assessment. There are a range of tools and approaches that can

be used to understand these experiences and support quality assessment in relation to care provision.

Patient-Reported Outcome Measures (PROMs)

Healthcare services can strive to understand the impact of their care on outcomes that matter to patients using patient-reported outcome measures (PROMs) [29]. PROMs are specific standardised tools that measure patients' perceptions of their health, function, and well-being using set questions or rating scales [30]. PROMs are generally completed by patients themselves and can be either disease-specific or more generic [31]. Both approaches use specific questions or rating scales to quantify outcomes that can be re-assessed on either a patient or service level over time.

A range of dental care outcomes can be measured with PROMs. Mittal et al. [32] identified 53 examples of dental PROMs. These fell into four categories: oral function, orofacial pain, orofacial appearance, and psychosocial impact of dental care. Grossman et al. [33] demonstrate specific PROMs for oral surgery, which identify, from the patients' perspective factors such as how long it took patients to achieve their normal activities, or if they needed further surgery or sought further advice post-operatively. In addition, a number of specific measures can be used in Oral Medicine [34].

PROMs have a range of roles in supporting quality improvement, specifically in supporting monitoring of healthcare quality and supporting decision-making. In addition, they can be used as outcome measures for research. The development of PROMs should proactively involve patients and undergo a robust evaluation to ensure they are suitable for their intended purpose [35]. Considering the nature of dental care for older people, existing PROMs may only be partly relevant or relevant in relation to aspects of dental care. More generic dental PROMs may not apply to situations such as when patients are receiving palliative care or when a cognitive impairment affects a person's experience of care. Specific PROMs would need to be developed in such scenarios.

Patient-Reported Experience Measures (PREMs)

When considering patients' experiences, historic measures focused heavily on patient satisfaction. A challenge with this measure is its broad, ill-defined nature and how it can be impacted by a range of inter-dependent factors, such as the experience of care, a person's expectations, and the nature or quality of care actually delivered [30]. Though a good outcome of care is desirable, patients' care experiences are another critical domain of quality. This can also be determined using specific measures, known as PREMs (patient-reported experience measures). PREMs mirror PROMs in using set questions and patients' self-reports, yet the nature of questions within the instruments differs. PREMs aim to identify what actually happened in a clinical visit by explicitly asking about particular processes

or events [30]. Generic examples of PREMs include whether a procedure or investigation was explained, or if a clinician introduced themselves, or if they waited longer than a specific time. PREMs have also been used in dental care, though evidence of their use relates primarily to oral surgery practice [33, 36]. These studies use PREMs that include questions relating to involvement in decision-making, intra-operative pain management, and the opportunity to ask questions.

When they have been appropriately developed and evaluated, these measures should allow specific aspects of experience to be addressed, particularly adverse experiences. The use of PREMs in dentistry beyond oral surgery is not widely documented, and the experiences of older people and their family and carers are not incorporated into any PREMs that can be currently identified, though aspects of generic PREMs will apply. PREMs can be used alongside PROMs to “produce a more rounded picture of patients’ views on both the process and the outcome of care”, yet a range of challenges may limit these measures guiding service improvement [37]. A cultural change is needed in healthcare settings to ensure that value is placed on person-centred care and to allocate resources to providing care in this way. Staff should also be empowered to support the translation of outcome measures into actual changes in service delivery [38].

Co-Design

The desire to include users’ perspectives and experiences has led to a rise in the use of design methods to develop and improve healthcare services [39]. Co-design is an approach which seeks to involve and empower non-designers to work alongside designers in the design process [40]. Often implemented through service design,

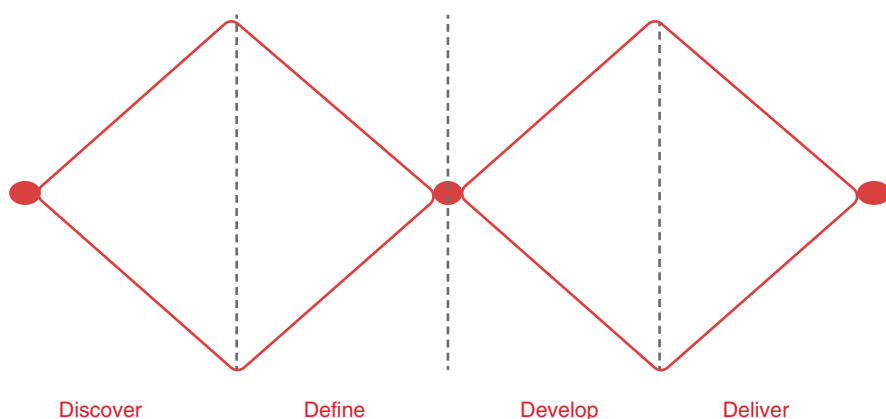


Fig. 3.4 The double diamond model of co-design from the UK Design Council [42]. The ‘discover’ phase engages with peoples’ experience in the beginning of co-design but continues to use this experience over time

co-design is grounded in the belief of a partnership approach to the design of services that includes those experienced in receiving and delivering services [41].

A common approach to co-design, The UK Design Council's Double Diamond Model [42] takes participants through a series of divergent and convergent thinking shown in Fig. 3.4. Participants are involved in all stages of the process, from understanding relevant experiences, through to translating these into potential ideas before then deciding upon which of these ideas to take forward through a process of iterative prototyping. Traditionally delivered through a series of workshops, in response to the COVID-19 pandemic a wider variety of creative approaches has been used to conduct activities [43].

A co-design approach seeks to uncover and understand patient experiences (along with a wide range of other stakeholders) and then uses this understanding to (re) design healthcare services. Visual and creative methods allow structured space for participants to share their experiences (Fig. 3.5). These methods embody a fundamental underpinning of co-design; the reduction of power and hierarchy, where no one person's skills or experience will be preferenced over another's. This provides a supportive activity-based environment which allows those with valuable lived experience to have the confidence to express ideas and surface latent knowledge around their values and feelings. The visual nature of co-design allows participants to externalise ideas, and see that they have been valued, listened to and acted upon [44].

It is essential to adapt any research process to meet individual requirements, ensuring that participants can engage in activities and attend sessions to share their experiences. Co-design activities can also be supported by other research methods, including ethnographic methods (where processes or people are observed) or other qualitative methods (such as interviews or focus groups), the data from which can

Fig. 3.5 Participants taking part in a co-design workshop and sharing their experiences



be visualised and fed into the process. The value of co-design approaches in health-care is that outcomes are more likely to be context specific and implementable in practice [45]. The sharing of various stakeholder experiences, allows mutual understanding and empathy, resulting in a change in perspective that feeds into the outcome of the process.

Research

Research aims to address a specific question and generate new knowledge. In the design of any studies, the involvement of people with lived experience is crucial; such individuals can support the prioritisation of research questions and the practicalities of study design and conduct to ensure research is acceptable and appropriate in the eyes of those it intends to benefit [46]. Such an approach is deemed so important that national standards exist on how it should be integrated into the design of research [47]. Some researchers have even gone as far as including patient representatives as co-authors in research projects including the authors of this chapter, a dentist and a former carer, who have conducted research together [48].

Research can either be quantitative, such as measuring outcomes numerically (for example, using PROMs or measurements of the number of teeth) or qualitative, using non-numerical data. Qualitative methods can be highly insightful and illuminate aspects of health care not amenable to numeric measurements, such as the impact of social and political factors on healthcare services and patients' experiences [49].

When seeking to understand peoples' experiences, a range of qualitative research methods can be used, as summarised in relevant methodological texts [50–52]. One qualitative approach is ethnography, where the delivery of care is observed by a researcher integrating themselves into a healthcare environment. There are a range of complexities in using such an approach, but it can provide insight that may not be gained from speaking to individual outside of a healthcare environment. The mainstay of qualitative research, however, is the use of interviews. Though this can be highly structured using a set list of questions, it can also be unstructured or partly-structured to allow a participant to speak freely to share their experiences. When interviews are undertaken with multiple individuals, the process can offer invaluable insight into under-explored phenomena. Interviews in a research setting are generally analysed in a formal planned manner to generate new knowledge or theoretical understanding that come from the sum of the qualitative data captured from talking to patients. The understanding can feed to both service improvement and the generation of interventions that can be applied within the clinical setting. Qualitative research can also support co-design as described above, which can be used as a research method as well as

an approach to service improvement. Dentists using qualitative methods and co-design must be mindful of how their own views and experience, particularly their professional status, may impact on their approach to interviewing and analysing interview data [53].

Conclusion

As demonstrated in the stories presented, the needs and preferences of patients can vary drastically. Patients' experiences can vary based on factors ranging from service availability to their or their relatives' attitudes and motivation to receive dental care. Focusing on what is felt to be "ideal" in research and service design fails to account for individual variation. To optimise a service, those using it must be invited to comment and share their experiences related to use of the services and these views have to be listened to carefully. The stories presented highlight the unique insight of those using services or supporting someone else to do so. The lived experiences of such individuals could support a transformation of service in a manner that a clinical team alone may not be able to. Mandy's story described how simple changes vastly improved her dental care experiences, whilst Holly's story provided insight into how a specialist service could provide the necessary support in a complex scenario. In contrast, Mary's story showed a situation with significant apathy toward dental care and the need for a relative to intervene to drive things forward. Relatives can support care improvement alongside patients themselves and dental services and teams must proactively seek these views to understand and improve the quality of care that can be delivered.

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