Beyond ingress: Analyzing and extending the meaning of access to healthcare

ABSTRACT

We argue that continuing to accept current views of healthcare access not only confines our appreciation of what access actually involves, but also restricts management understanding of what is required from healthcare organizations in order to tackle access barriers currently hindering the realization of health benefits for many people. Consequently, we proffer a new theoretical framework that conceptualizes healthcare access as a journey towards benefit realization. At each journey stage are myriad contrivances which enable or constrain progress. Illustrating our framework with data from an extensive multimethod mixed methods approach to the study of hospice and end of life care, we show how it overcomes the limitations inherent in current access frameworks, broadens our understanding of what healthcare access actually means, and provides a context that enables the identification of previously concealed barriers. As such, our framework offers a new way of considering healthcare access that can contribute to overcoming the numerous obstacles and spatial inequalities currently found when people attempt to access many healthcare services.

INTRODUCTION

The whole corroboration, you need to know what's available, what it does, how you get access to it, and what the benefits are…because you're walking into a strange world; my heart goes out to people that aren't able to ask the questions, because there are an awful lot of people that can't

[Pete, patient's husband].

The importance of access to quality healthcare services for physical, mental, and social wellbeing is undisputed. Yet, about half of the world's population is unable to access the healthcare services they need (UN, 2017), and, as Pete in our opening vignette explains, many healthcare services are confusing and disconcerting for patients and their families. A well-researched dimension of access is affordability (Healthy People, 2020). However, even in countries such as the UK where healthcare services are free at the point of delivery, access barriers are numerous and spatial inequities long-standing (Bradshaw, Bloor, & Doran, 2018). The concept of access to healthcare goes beyond physical location to encompass access to the right person, the right care, at the right time (NHS, 2021a). Consequently, researchers tend to use the well-known frameworks of Aday and Andersen (1974) or Penchansky and Thomas (1981) to assess dimensions of access such as availability, acceptability, adequacy, and geographic accessibility (Saurman, 2016). These frameworks conceptualize access as a concept relating to consumers' ability or willingness to enter into a healthcare system (Penchansky & Thomas, 1981) dependent upon properties of the system (availability of clinical appointments) and/or the individual (ability to afford).

We argue that continuing to accept this view of healthcare access confines our appreciation of what access actually involves, therefore restricting manager's understanding of what is required from healthcare services in order to tackle access barriers currently hindering

the realization of health benefits for many people. Drawing on the work of Ribot and Peluso (2003), we proffer an alternative conceptualization of healthcare access which not only identifies individual and systemic barriers, but broadens our understanding of what healthcare access actually means. Current perspectives intimate that improving access pertains to increasing people's right to healthcare by expanding opportunities to enter the system (more appointments or accessible healthcare clinics). While important, this perspective is limited insofar as improving people's opportunities or right to access does not automatically equate to their ability to benefit. Hence, we reconceptualize healthcare access as *the ability to realize health benefits*. This reconceptualization expands our attention from solely gaining entry to the right person, and the right place, at the right time, to a focus on how, even when an individual gains admission to the healthcare system, myriad barriers to gaining benefit still exist. As Pete in our opening vignette articulates, walking into a strange world - even after managing to navigate the many barriers to entry - does not automatically equate to the agency required to benefit from it.

We build our new healthcare access framework in one particular dimension of healthcare: that of hospice and end of life care (EOLC). EOLC is the point at which care shifts away from curative treatment toward a focus on quality of life and quality of death for people with terminal illnesses. EOLC is a core business of medicine (Higginson, 2016), an ethical responsibility of health systems (WHO, 2021), and a service that around 20 million patients require each year (WHO, 2021). Yet, only a miniscule proportion of healthcare research focuses on it (Higginson, 2016). It is also an area of healthcare where barriers to access are particularly prevalent (Parajuli et al., 2020). We make three contributions. First, we challenge the dominant model of healthcare access and instead offer a new perspective that extends and enriches current thinking. Second, we provide analysis of a seven-year comprehensive study into hospice and EOLC. In contrast to

extant literatures which examine access barriers from the perspective of marginalized non-users or light service users, we analyze the experiences of the privileged: defined here as people who actually attained entry into hospice. By taking our unique view of access, we uncover previously undetected insights into the barriers faced by people who need EOLC and the ways in which current systems, processes, and perceptions can hinder a person's ability to benefit from it. Finally, we contribute practical recommendations and suggestions for the ways in which managers can enhance healthcare access for the people who need it.

The Concept of Access

Healthcare access dialogue is ubiquitous and long standing, comprising policies, guidelines, and extensive research articles (Núñez et al., 2020). Its most basic conceptualization is the ease at which consumers can enter a healthcare system and their willingness to do so (Aday & Andersen, 1974). Ease of entry focuses on supply features such as infrastructure and availability of resources, usually treated as mediating variables that impact admittance (Saurman, 2016). Willingness and ability, which pertain to individual and community characteristics, are the focus of much work on access equity, particularly for marginalized and disadvantaged groups (Zhao, Cao, & Ma, 2020). The Andersen framework (Aday & Andersen, 1974), also called the sociobehavioral model of health services use, is the best known healthcare access model (Ricketts & Goldsmith, 2005). The framework incorporates supply and demand characteristics together with consumer satisfaction ratings against criteria such as waiting times and availability of appointments. Penchansky and Thomas (1981) extended the Andersen model, redefining access as representing the degree of fit between the characteristics of the healthcare system and the characteristics and expectations of the client, and synthesized the different but related

dimensions of access into a taxonomy comprising availability, accessibility, accommodation, acceptability, and affordability. These authors positioned the taxonomy as useful to measure satisfaction and explore consumer behavior and patterns that influence utilization. These two models, and derivatives of them, comprise thousands of studies that evaluate access to a wide spectrum of healthcare services, though few focus on access to EOLC.

Sometimes, research defines access as opportunities to use or ease of use; here the attention is almost always on spatial issues with availability and infrastructure dominating (Rader et al., 2020). More typical is the employment of utilization rates as a proxy for access (Detollenaere et al., 2017). Even when studies are careful to include definitions of access that embrace "realized need" (Peters et al., 2008:161), research consistently conceptualizes 'realized need' as actual use – defined as making contact with a healthcare system (Zhao et al., 2020). Hence, from this perspective, as long as a patient has visited an outpatient clinic, or attended a doctor's appointment, they have successfully accessed a healthcare service. However, the 'opportunities to use' model falls short because it assumes availability equates to need, while the utilization model assumes receipt is adequate (Dixon-Woods et al., 2006). Neither perspective takes a user-focused standpoint, which is becoming increasingly important as part of the healthcare paradigm shift marking passive patient to active consumer (Bokhour et al., 2018). Policy takes the standpoint that access to healthcare is a human right, which in turn places obligation on states to provide healthcare access (WHO, 2017). Policy then assesses levels of need by levels of ill-health, mainly because health status measures are easily available (Smith & Connolly, 2020). However, counting the number of people diagnosed with different illnesses does not take into consideration comorbidities or different levels of disease complexity. Policy measures also use usage rates, which perpetuates the focus on utilization, particularly among

marginalized and disadvantaged groups. Thus, while long recognized as problematic (Tanner, Vann, & Kizilova, 2020), the utilization definition remains pervasive, probably because realized access is relatively easy to measure, while evaluating capacity to benefit is highly complex (Smith & Connolly, 2020). Unsurprisingly, there are many recent calls for research to address the challenges inherent in healthcare access (Macdonald et al., 2016), though due to its complexity "there are no definitive answers in sight" (Núñez et al., 2020:2).

Access as the Ability to Derive Benefits

In response, we suggest a reinterpretation of healthcare access from opportunities to use or utilization rates to one of ability to realize health benefits. We base our definition on Ribot and Peluso's (2003:153) theory of access for property and natural resource analyses, which shifted property's traditional definition of the "the right to benefit" to "the ability to derive benefits". Access, from this perspective, becomes analogous to a bundle of powers which incorporate social relations as well as the mechanisms and processes that restrain or enable a person to benefit. The distinction between right and ability is important: right suggests codified principles which, in the case of healthcare, take us back to issues of infrastructure and universal coverage ideologies. Ability to realize benefits encompasses a much wider range of issues, including social dynamics and agency. Access, from this perspective, "is about *all* possible means by which a person is able to benefit from things" (Ribot & Peluso, 2003:156), broadening the stance beyond codified spheres to encompass any political, economic, cultural, social, or conventional issue that either enables or constrains an individual's ability to derive benefit.

In Ribot and Peluso's (2003) original theory, access comprises gaining, controlling, and maintaining access to natural resources, with access analysis the process of detecting the

mechanisms which facilitate or obstruct. These mechanisms include rights, illicit practices, and structural and relational contrivances such as capital, markets, labor, knowledge, authority, identities, and social relations. The theory has been influential in enhancing understanding of land control, land grabbing, environmental conservation, and access to scarce resources including water supply, markets, and food distribution systems, usually in the Global South (Faye & Ribot, 2017; Gimelli, Bos, & Rogers, 2018). It is also included in two studies into healthcare access. The first focuses on access to maternal healthcare services in rural Ghana since the introduction of the national health insurance policy (Abdulai & Adams, 2018), while the second (Jafree & Sastry, 2020) use uses it as one of several theories to understand health behavior of South Asian women.

We use Ribot and Peluso's (2003) theory of access as our starting point to build a theoretical framework of healthcare access in several novel ways. In contrast to the thousands of published studies that cite the original theory, our research emerges from the Global North; in a country that, ranking difficulties notwithstanding, appears consistently among the top-rated countries in the world for overall healthcare provision (Schneider et al., 2017) and is exemplary in terms of its EOLC services (EIU, 2015). Further, we develop our model by examining barriers to access not from the perspective of an impoverished group, but among those who did gain entry to hospice care, those, from the utilization perspective, who did gain access. This new lens enables examination of equity issues in greater depth than hitherto, as well as uncovering previously invisible access barriers. Finally, given its potential to uncover previously unseen access barriers, our framework has the potential to improve societal outcomes, thus answering calls for our field to better address problems that can positively impact a wide range of stakeholders, therefore creating a better world.

METHODOLOGY

Our seven-year empirical project comprises work in healthcare management, customer experience, and service design, and the introduction of a kernel theory with its roots in urban sociology clearly positions our study at the point of interaction between disciplinary borders. Leaving the confines of our disciplinary boundaries has entailed engaging with a turbulent landscape characterized by methods, theories, and epistemic divisions with the ambition of instigating real change; for which multimethod mixed methods research is apposite for its synergistic potential (Hesse-Biber, 2015). The outcome is a rich extended case study (Burawoy, 1998), a reflexive science approach to data collection and analysis that seeks theory reconstruction and lends itself well to complex health service research (Crowe et al., 2011).

Case Study Setting

Our case is set in the UK, which leads the way for quality of death rankings (EIU, 2015) and includes 245 patients and their families who were receiving care from 9 different hospices and EOLC hospital units. The hospices deliver care in small inpatient units for around 17% of patients, while the rest receive care in care homes or their own homes. Because hospice care focuses on quality of life toward end of life through grief support for the bereaved, it concentrates on pain management and other physical problems combined with addressing psychosocial and spiritual needs (Hospice UK, 2021). Consequently, this holistic approach incorporates different actors including general healthcare professionals such as general practitioners (GPs) and community nurses, and specialist palliative care (SPC) providers such as hospice doctors and nurses. Family caregivers are both important providers of EOLC (Perpiñá-Galvañ et al., 2019) and recipients of support before and after bereavement (Hospice UK, 2021).

Well attested benefits of EOLC include quality of life enhancements for patients and families, promotion of dignity, comfort, and emotional and spiritual wellbeing at end of life, alleviation of caregiver burden, enabling people to die at home if they so choose, and easing bereavement (Carr, Boerner, & Moorman, 2020; Gomes et al,. 2016). Such care costs significantly less than treatments that focus on cure (Hoverman et al., 2020) and reduces utilization and costs of acute hospital services (CAPC, 2019; Wright, Youens, & Moorin, 2017). Forecasts suggest dramatic increases in demand for hospice care in the coming decades due to the large cohort of aging baby boomers and increasing prevalence of comorbidities (CAPC, 2019; Cruz-Oliver, 2017; Etkind et al., 2017). At the same time, there are fewer familial caregivers due to smaller and more fragmented families and an increase in retirement age (van Groenou & De Boer, 2016). High numbers of deaths in acute hospitals are not sustainable, hence expansion of EOLC across all settings is a pressing need (Gomes et al., 2016). Yet, despite progress, large numbers of Americans are unable to access this type of care (CAPC, 2019), and in the UK, one quarter of all families miss out on crucial end of life support (NICE, 2019).

Data Collection

Pathographies. We collected 245 pathographies from patients (83), current caregivers (75), and bereaved caregivers (87). Pathographies are stories of illness experiences; experiential narratives that put the patient at the center. Pathographies facilitate data collection from the individual's perspective rather than using predetermined questions, and enable a longitudinal perspective: they start prior to encounters with healthcare systems and incorporate the whole patient journey (Hunsaker Hawkins, 1999). These advantages are key to reflexive science

processes, allowing the researcher to move with participants through their space and time (Burawoy, 1998). Pathographies were audio recorded and then transcribed verbatim.

Interviews. We conducted 32 in-depth interviews with a range of EOLC providers including specialist hospice and EOLC consultants and nurses, GPs, community nurses, hospital nurses who had administered EOLC in the previous 6 months, a hospital frailty consultant, and community care home managers. The interview schedule comprised questions pertaining to their views of micro, meso, and macro forces impacting EOLC, their experiences of referral to hospice, and their perceptions of EOLC benefits and unmet needs. These too were audio recorded and transcribed verbatim.

Survey. We administered a face-to-face survey comprising closed and open-ended questions to 100 hospital clinic outpatients who were waiting for diagnostic tests. Given this small convenience sample, we make no claims of representation or generalizability. Rather, we included this relatively small phase of data collection simply to give us a snapshot of the levels of awareness and knowledge of EOLC services among non-hospice patients.

Ethnography. We engaged in multiple rounds of participant observation with service providers, attending several national and international practitioner events, and more importantly, spent numerous days as observers in each of the 9 different units that collaborated with us. We wandered around wards and clinic areas, we sat in staff rooms and relative's lounges, and we spent time in hospice gardens, sometimes interacting with, sometimes solely observing patients with their families and clinical staff. We engaged with the senior and frontline staff of each unit, scoping out, in detail, each unit's unique service provision. We also moved from an etic to an emic approach when we participated in numerous staff 'away days' and 'strategy days', mixing with hospice nurses, doctors, volunteers, trustees, and CEOs. Several of these away days also

comprised clinicians from the wider healthcare system, including GPs and community nurses, enabling us to understand the perspectives of different actors and different micro-macro challenges. During these days, we not only observed but became 'overt insiders' (Jones & Smith, 2017) by participating in workshops and break-out sessions which facilitated a rich understanding of habitus and culture. This process becomes a form of knowledge production through action, and is apt for producing theory as well as realizing change (Shah, 2017).

Data Analysis

In keeping with the extended case method we thematized the data by building on Ribot and Peluso's (2003) preexisting definition of access and "extending out" (Burawoy, 1998:5). We realized that existing theories of healthcare access could not explain much of the phenomena we observed during our seven-year study. We therefore took an abductive approach by searching for potential explanations for the real events and happenings that we witnessed, and building new themes around them. This perspective brings to the fore novel insights and inconsistencies between normative statements and the real struggles – on behalf of patients, families, and providers – that we observed. We used the original definition that access is "the ability to derive benefits" (Ribot & Peluso, 2003:153) as our starting point. Three authors then conducted several individual iterations of manual thematic analysis, initially examining the pathography and interview data for themes that enabled or constricted people's ability to realize health benefits. We shared our analyses, taking a reflexive approach where we built on the pathography and interview data with our own field notes and observations from the wider ethnographic study, and engaged in phenomenon-construct mapping whereby we started with our observations and identified constructs and relationships that explain real-world phenomena (MacInnis et al.,

2020). We therefore describe our approach as abductive, interpretivist-constructionist, and reflexive.

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HEALTHCARE ACCESS: A JOURNEY TO BENEFIT REALIZATION

Figure 1 depicts our healthcare access framework. The model represents a journey which spans four stages (depicted across the top of the model) and three interrelated benefit realization assemblages (shown on the left hand side of the model) which we now explain.

Journey Stages

We theorize that the journey to health benefit realization comprises the stages of need recognition; acknowledgement; ingress; and benefit realization. Stage 1, need recognition, pertains to issues surrounding diagnosis and a recognition, on the part of both service user and provider, that movement to the next journey stage is required. Stage 2, acknowledgement, refers to the transitional stage between recognition of need and referral stage, which emerged as crucially important in our data, yet to our knowledge is unique in healthcare access frameworks. The third stage, which we term ingress, depicts referral processes and entry to the healthcare service under study, and is therefore the point at which most healthcare research and policy portrays access as complete. In our model, however, there is a fourth and final stage: that of benefit realization. In optimal situations service users move smoothly through the stages in order to realize health benefits. Importantly, though our conceptual model depicts the journey to access as comprising four linear stages, the stages represent zones within a liminal space, a process through which there are thresholds marking the journey from need recognition to benefit

realization. In reality, many users revert back a stage or more; they can be stuck at or between stages for varying lengths of time; and they can proceed through some stages relatively quickly.

Benefit Realization Assemblages

We propose that discernable within each journey stage are three interrelated assemblages - collections of contrivances that are both human and non-human - that enable or constrain a service user's ability to move to the next stage in order to realize benefits. These assemblages comprise communications, institutional characteristics, and agency.

Communications. A central proposition in our framework is that communication is crucial to multiple facets of a service user's journey to benefit realization, hence this assemblage comprises all communications pertaining to the healthcare service. In addition to communications between patients, families, and healthcare providers, it includes the benefit-related dialogue and understanding of the advantages pledged by the healthcare service; in other words, an understanding of the reason why the service exists. Whichever communications model we select, common to all is that communication is symbolic and transactional; a process of creating, interpreting, and negotiating meaning (Croucher, 2016). As Pete in our opening vignette reminds us, for most people accessing healthcare is a strange new world, where people do not know what is available (what are the different options?), what they do (what does each option entail?), how they access it (what are the stages and process required for admission?), and what value the service offers (what are the benefits?). In our theoretical framework of healthcare access, we refer to the communications assemblage as all facets of the dialogue that aid or hinder a service user in their journey to benefit realization. This assemblage therefore refers to the codes, language, and symbols used in organizational literature, the channels used, the design and

elucidation of the mission of the service, and the various clinical and non-clinical encounters that a service user has to negotiate.

Institutional Characteristics. The institutional characteristics assemblage refers to the holistic and complex healthcare service system through which actors need to navigate; comprising a system of smaller systems where components and networks should provide synergy. Key to success in complex systems are interconnections and linkages between actors and resources, which are particularly important in healthcare services in order to deliver integrated care and consider the whole person, rather than solely the disease (Grudniewicz et al., 2018). Yet, despite recognition of the worth of complex systems thinking, policy and much healthcare research focuses on specific clinical micro systems such as the emergency department, or particular aspects of interconnections such as teamwork (Waring, Marshall, & Bishop, 2015). In reality, many healthcare journeys encompass movement between care providers and situations, and users need to navigate the processes within and between these different entities.

Agency. This assemblage refers to actor's resources which, when leveraged, can aid navigation. Here agency incorporates information, knowledge, social networks, and any other resources an actor has and can use to leverage their capacity to make choices in their quest to realize benefits. Examination of the ways in which actors exercise individual agency and, connected by shared institutional arrangements, develop collective agency, is key to benefit realization.

Analyzing the Journey to Benefit Realization

From our perspective access analysis, or what we term the ability to realize health benefits, is the process of identifying and mapping any contrivance which enables or constrains benefit realization. These contrivances are numerous and varied, but for ease of use we suggest that each can be classified into one of the theoretical interrelated benefit assemblages. The individual contrivances are dynamic and diverse, comprising micro, meso, and macro level forces and factors that shape and impact a person's healthcare journey to benefit realization. As changes to communications, systems, and power relationships occur, so too will the individual contrivances change and shape the benefit realization journey. Undoubtedly, some enablers and barriers are likely to be common to multiple healthcare services, while others will be specific to the particular healthcare service under study. Nevertheless, we suggest that our basic framework with its four stages and three interrelated assemblages is suitable for mapping any journey to benefit realization for any healthcare service, at any point in time.

While our journey stages and the interrelated assemblages are theoretical, we suggest that in order to identify and fully understand previously undetected enablers and constraints, mapping the journey to benefit realization is an empirical exercise. Though each journey is unique, it is possible to identify patterns common to multiple journeys. We therefore now turn to an illustration with examples of the contrivances – the enablers and barriers (illustrated in the pale grey boxes in figure 1) - that we identified in our EOLC case study. We structure the following discussion by following the journey throughout each stage, discussing the assemblages within each. It would be just as possible to use the framework to examine each of the assemblages and how they change depending on the journey stage in question. For now, though, we follow our

model on a stage by stage (column by column) basis, illustrating some key findings within each box of Figure 1.

AN EMPIRICAL ILLUSTRATION TO EOLC BENEFIT REALIZATION

Journey Stage 1: Need Recognition

Communications and the realm of understanding. Clarity of communications emerged as crucial at this first part of the patient journey, which relates to the point of diagnosis with a terminal illness. Patients – entering a strange new world – require information that is clear and accessible, with our empirical study spotlighted the importance of people understanding the benefits of EOLC. However, we identified numerous communications barriers caused by a misalignment between understanding needs and understanding how EOLC could help. We have termed these barriers the realm of understanding (see Figure 1). Long ago Schramm (1955) explained that fundamental to successful communication is a commonness between sender and receiver, termed the realm of understanding. The sender encodes and the receiver decodes in their own field of experience. Too often these fields did not fully overlap, hindering communication: *"this was the problem, they were talking about these care packages but we didn't know what they were and where to start"* [Sam, Bereaved Husband]. As patients enter this strange new world, the introduction of language that is both alien and frightening produces noise – a barrier to effective decoding of information: *"It's confusing because the initial diagnosis wasn't really a diagnosis it was just the GP telling us that he thinks that it's secondary cancer. So, we really didn't know what to do with that information. You feel like you want to ask so many questions but you don't know what questions to ask. We just came home and we were a bit numb.*

And because it wasn't an official diagnosis…you put it to the back of your mind" [Doris, Patient's Wife].

We also found myths surrounding hospice and EOLC, though long recognized (Naierman 2013), to be clearly prevalent: *"just the word hospice terrifies you"* [Paula, Patient's Mother], with many referring to hospice as *'the death house'* accompanied by imaginings of *'an old person's care home'* or a place that actually speeds up death: *"if I take him there, then that's it…he's gone"* [Jo, Bereaved Mother]. Possible underlying reasons for the perpetuation of such myths include poor performance on the part of governments and the hospice movement itself in communicating the very real benefits of good EOLC (Cruz-Oliver, 2017; Naierman, 2013). Consequently, these barriers often cause delays to the patient journey, with many examples of disorientation among patients and their families at this early stage. Unfortunately, many of the communications methods also failed to get a clear message out. Some channels were inappropriate for the patient population, *"the problem with websites is things are buried away and unless you're maybe 21 and focused entirely on the internet for your life, I don't think you become an expert at delving everything out of it"* [Jim, Patient's Husband]. For others, due to the enormity of what people are facing, they close their minds to traditional communication methods: *"we were given some leaflets as well… I binned them"* [Lisa, Parent].

Institutional characteristics and EOLC training. Moving to institutional characteristics, we identified a lack of training among non-specialist providers to be a major barrier to patient journeys, which coincides with a shortage of trained specialist providers. Much EOLC is provided to patient's in their homes, yet *"you haven't got the experienced community nurses to support the complexity of end-of-life care"* [Shelley, hospital nurse]. Indeed, some professionals admitted they felt out of their depth, despite the fact that their job roles expect them to administer

EOLC: "*We've got no experience of end of life care from the teaching that we've just had, it's something that you learn on the job from scratch and that is very, very daunting because it's not just the medication, it's engaging with the patient, it's everything, and it's overwhelming*" [Libby, community nurse]. Indeed, research shows that formal EOLC training is inadequate, possibly because EOLC originated from community hospice programs rather than organized medicine (Dalal & Bruera, 2017). Studies clearly show that hospice costs significantly less than other medical costs (Huang et al., 2020), with dying at home under hospice care costing half of dying at hospital (Hoverman et al., 2020), yet unless more resources are put into EOLC training, these potential long term cost savings will go unrealized.

    Agency and power imbalance. Recall that the benefit assemblages are interrelated, and we have already seen of a lack of agency for patients and families regarding understanding what hospice and EOLC entails, while agency is restricted for some practitioners due to insufficient training. In this final assemblage in this stage of our model, we focus on the large power imbalance between patients and families on one hand, and clinicians on the other. We acknowledge that it is difficult to think of many examples where people are less vulnerable than when at end of life. We witnessed people lament their lost agency, telling us stories of their previously powerful and successful careers and sharing overwhelming feelings of helplessness now, as their failing bodies led to a dependence on others. At this initial journey stage, power imbalances became apparent for three major reasons. First, an absence of priming and the subsequent confusion after diagnosis was evident in many pathographies: *"we were brought into a room and there was a lady in day clothes sitting there and I wondered what she was there for. Then the doctor turned the screen around and said "there are tumors there, there, and there". And I had no inkling. I said, "Are you saying she has cancer? I thought we were following up*

from the heart attack?" He was actually indignant when he confirmed that it was malignant and *too far gone for chemotherapy"* [Tim, Bereaved Husband]. Of course, there is no easy way to tell someone they have terminal cancer. But few would argue against there being better ways than the occurrence in the service encounter this example illustrates.

Second, differing levels of health literacy made encounters difficult: *"trying to educate patients on the latest research can be challenging because they've got old fashioned points of view and understanding of how they would treat themselves"* [Karen, Nurse]. Karen's summary, though sweeping, is perhaps reflective of the relatively low levels of health literacy found in the general population. Health literacy or "a person's ability to understand and use information to make decisions about their health" (NHS, 2021b) is found to be low in a quarter of the US population (Hickey et al., 2018), while one in four British adults struggle with public health content (NHS, 2021b).

Third, and perhaps relating to health literacy and contrary to the much acclaimed paradigm of patient empowerment (Feder, Akgün, & Schulman-Green, 2020), we identified a perception among many people of the superiority of clinicians, which perpetuated feelings of helplessness: *"Why did he use a Latin name? Why didn't he say that it's cancer? This is my cancer! But because he was a qualified doctor he thought he was better than me, and he called it by its Latin name. Asshole. The only person that looked stupid was him"* [David, Patient]. Closer to home was an experience during one of the 'away-days' when, during a feedback session, we were taken to task by a dumbfounded doctor for calling his 'patients' 'healthcare consumers'.

Journey Stage 2: Acknowledgement.

Eventually, some people transition to the second journey stage, where they begin to acknowledge the severity of their illness and their need for help. Nevertheless, our data clearly revealed lingering reluctance here, a liminal space between recognition that they need help and actual entrance into the system. As Figure 1 shows, key barriers within the assemblages at this stage comprised timing, institutional logics, and fear.

Communications and timing. Within the communications assemblage, we identified timing issues as a major underlying cause for hesitancy. Timing issues, usually due to uncertain disease trajectories, caused indecision: *"my two children thought it should have been earlier than I did, I didn't want to introduce Chloe too early as I didn't know how long the journey was going to be, I still don't"* [Brian, Husband]. This barrier did not just arise from patients. We identified it among GPs, too, who expressed concern over never being quite sure of the correct time to refer to EOLC, with some suggesting referral at the point of terminal diagnosis, while others felt it was only at the point when EOLC services could offer something extra that they acknowledged the time was right to refer. GP referral to specialist services, within and outside EOLC, is a core feature of primary care and therefore attracts attention in the wider healthcare literature which recognizes professional judgement as a factor that impacts the decision (Walton et al., 2018). Yet, when the literature pertaining to access does discuss timeliness, the focus is usually on appointment waiting times (Aday & Andersen, 1974; Penchansky & Thomas, 1981), often omitting this crucially important dimension of potential delay. Of course, it is often impossible to put a timeline on a disease trajectory. The issue here refers to communications in terms of explaining the benefits of earlier rather than later referral. Research shows that early entry into EOLC is beneficial in terms of reducing unplanned visits to the emergency department and fewer

unplanned hospitalizations (Wright et al., 2018). Yet, there was little knowledge of this among our actors.

The timing of conversations about end-of-life also caused lingering at this journey stage. The taboo of talking about death makes people flounder in their decision making: *"people don't talk about it, don't talk to their families about it, it's all very hush hush when we're all going to die and that's the simple truth and we should talk about it when we still have capacity to talk about it. If we leave these conversations for later, we don't know what our loved ones would want"* [Sue, Care Home Manager]. Often a crisis state marked by mental and physical exhaustion for families, where *"the situation at home was deteriorating… 'eventually I said 'look, we can't manage'"* [Gail, Bereaved Wife], coupled with persuasion from others *"she said, it's for your own good. I looked at her and I couldn't understand it, really"* [Val, Patient], and being *'lucky'* because *"a friend of mine, his wife comes and works at the hospice as a volunteer, so we got some background off her about it"* [Greg, Husband] eventually aids progression.

Institutional characteristics and logics. Within the second assemblage, institutional logics emerged as a major barrier to accessing EOLC. In our case, different perspectives between different actors emerged as a major cause of delay. Even among experienced clinicians, differing institutional logics resulting from training, medical specialisms, and internalized mental schemata led to differences in acknowledgement for the need to move from curative care to palliation, as this quote from a hospital nurse illustrates: *"she [doctor] looked at me and said, but that is a sortable condition, and I wanted to say yes, but his life isn't…I think at an acute hospital they want to cure what is in front of them and they don't get the bigger picture"* [Emma]. This quote exemplifies both the power struggles between different clinician levels (doctors and nurses) and the disciplinary boundaries that exist when clinicians from different

medical disciplines espouse different and sometimes contradictory approaches to care (Liberati, Gorli, & Scaratti, 2016).

Agency and fear. Many respondents explained feelings of confusion and disbelief around diagnosis *"you're in shock and you don't hear half of what they tell you anyway"* [Alan, Patient], which led to fear and a type of 'brain fog' that left them feeling helpless and caused journey delays at this stage. Nurses, too, felt rather lost at this stage, describing it as a type of liminal space between need recognition (on the part of the nurse) and denial on the part of patients who often lacked understanding regarding the severity of their illnesses, and families who demand curative treatment long after it is likely to work. This situation resulted in many providers feeling helpless themselves: *"they are end-of-life, yet haven't had that DNRCPR [do not attempt resuscitation] conversation…I don't feel it's my place to have that… it's just a horrible situation to be in"* [Jade, Nurse].

Journey Stage 3: Ingress.

This third stage of our model, entitled ingress, is the point at which traditional models confirm access to the healthcare service. We identified barriers and enablers within each of the assemblages, comprising gatekeeper dialogue, institutional arrangements, and proxy agency.

Communications and gatekeeper dialogue. Even when some people had progressed through the liminal stage of acknowledgement and realized they needed to enter EOLC, dialogue with gatekeepers acted as a barrier to smooth access. *"We rang MacMillan [Cancer Charity] and got no help whatsoever, the only thing we got out of them was a letter asking us for money. They didn't seem to understand that we were floundering, completely floundering"* [Jan, Bereaved Wife]. We heard of countless examples of communications problems between patients

and gatekeepers, including GPs, GP receptionists, hospital clinicians, and community nurses who delayed referral even when patients and their families were ready to enter EOLC: *"I don't know why the GP had not mentioned it, we needed it earlier, a lot earlier… because we have struggled"* (Helen, Patient's Wife). There were also communications problems between different gatekeepers, including when and how to refer patients to EOLC.

Institutional arrangements. Many barriers and enablers to referral within the institutional characteristics assemblage pertain to arrangements for interconnections between parts of the system. Too often, the story was like this: *"you're told [at the hospital] you've got Motor Neuron Disease, which has only got 6 months to 3 years survival rate. So we're told by him [doctor], and that's it, I walked out the door with nothing, no information, he said 'the specialist nurse will contact you', which was 7 weeks later and it took us 6 months from the time that Barbara was diagnosed to get to the stage that we had all the various people in place"* [Jack, Patient's Husband]. Institutional arrangements greatly impacted interconnections, as the wife of one patient explained: *"something that I have found really difficult, we go to the specialist cancer hospital and say he is fatigued or breathless or something, they say go to the GP so we are permanently there, but sometimes we need the hospice because he needs something outside medical intervention; what I am finding is I don't know when I should go where, and because he's on the neurology side of oncology he has 6 or 7 different types of things going wrong, and now he's getting blood clots but we had to go via the GP and he referred to the normal hospital and that is not linked in with the specialist at the cancer hospital"* [Kate]. Healthcare systems worldwide are moving from a functional organization to a multidisciplinary team approach in order to deal with complexity and ensure a patient-centered approach. Yet, as Liberati et al. (2016, p.32) candidly note, "the mere juxtaposition of professionals….does not

guarantee effective collaboration towards the delivery of integrated patient care". Certainly our data supports previous research that suggests changes to the institutional arrangements required to enable collaboration are still in their infancy. Importantly, providers also lamented institutional arrangements that hindered them and added to feelings of frustration due to lack of sufficient resources, within system linkages, and alien institutional logics that hinder collaboration.

Proxy agency. Even at this penultimate journey stage we found little agency among patients themselves. However, at this point families tended to find a way to break down barriers. Thus, it was only through proxy agency, a socially-mediated type of agency (Bandura 2006), that patients were able to navigate their journey at this stage. Proxy agency among families began to replace the overwhelming absence of agency so apparent in earlier journey stages. We found many examples of proxy agency where relatives intervened on behalf of the patient to ensure referral and regain some control: *"After an x-ray a fortnight previous, and still no appointment, I phoned the hospital myself. I had to phone to get an appointment for John to be told they couldn't do anymore for him. Then after days I had to phone the GP… they'd all left me sitting at home with a very ill man"* [Ruth, Patients Wife].

Journey Stage 4: Benefit Realization

Recall that in our model, healthcare access occurs only at the point of realized benefits. In our study, we found benefit realization to come from clarity of communications, person centered care, and collaboration.

Communications clarity. Countless examples of clear communications and appropriate non-verbal communications enabled benefit realization, with an overwhelming and wistful

feeling summed up in the simple expression, *"I wish we'd done it sooner… we just didn't know what to expect"* [Liz, Wife]. This latter quote is poignant on several levels. It reflects the regret expressed by so many patients and their families who lamented the parts they had played in delaying access in the earlier journey stages. It also spotlights the vast chasm between EOLC services and most people's perceptions of them. Even at this stage, however, a lack of clear communications hindered some people's ability to benefit. Indeed, we uncovered a whole spectrum from one extreme *"I have no idea why I'm here, I think I am a lost event, I think I am dying…"* [Ethel, Patient], to the other, illustrated by this quote from the mother of a child at end of life: *"we're quite prepared now. I said to the doctor, 'tell me how it's going to happen, talk me through the process', and she has, and I trust her"* [Abbie].

   Institutional characteristics and person centered care. Person centered care is a health paradigm that calls for a holistic approach to wellbeing of both the patient and their family, and incorporates individual preferences (Santana et al., 2017). Striking is the difference between earlier journey experiences, *"16 of the worst weeks of my life… the hospital is appalling. I can't even begin, it would take an awful lot of time just to tell you how appalling it was"* [Cath, Bereaved Daughter], and the encounters experienced within hospice: *"I don't think they see the patient as a patient… they see them as, you know, a human being that has got families"* [Eve, Bereaved Wife] revealed a lack of person centered care prior to entry into EOLC, but we found many examples of it once people had managed to navigate earlier journey stages. Indeed, comparisons were numerous: *"a totally different world, I couldn't believe it"* [Kim, Patient's Sister], summed up in this darkly humorous note: *"to put it in simple terms it was like going to a holiday camp to die"* [Fred, Bereaved Husband].

Agency and collaboration. In this final assemblage at the final part of the journey, by agency and collaboration we mean that benefit realization occurred when stakeholders collaborated. Of course, to be able to collaborate requires agency in the form of sufficient freedom to act on the part of clinicians, and capability and capacity to act on the part of patients and families. Once in place, examples of benefit realization were overwhelming. Many clinicians, often working outside formal arrangements because *"there's no joined up thing and there's no proper care plan and there isn't enough time to order the equipment"* [Vicky, Nurse] told of the ways in which they somehow found collective agency (Bandura, 2006) and came together to collaborate in order to enable benefit realization. Often, benefit realization was only possible with the input of families, too, especially in situations where time is short to arrange hospital discharge to enable a person to die at home*: "if we have really good supportive families you can get people out, and it is about working together and really pulling out all the stops"* [Becky, Nurse]. Indeed, there is growing recognition of the centrality of family caregivers as important sources of physical and emotional support (Perpiñá-Galvañ et al., 2019). Our data mirrors these findings, and also demonstrates the wide range of practical support families give in terms of negotiating with gatekeepers, following up appointments and test results, and collaborating with different provider agents for the benefit of the patient.

DISCUSSION

As management scholars, we were fortunate (and honored) to be given such a rare opportunity to examine a particular type of healthcare that is under researched (Higginson, 2016), growing in demand (Etkind et al., 2017), and of utmost importance to global health and wellbeing (WHO, 2020). Our interaction with a broad spectrum of different actors (patients,

caregivers, bereaved families, and a wide variety of clinicians and managers) across different service dimensions (inpatient units, outpatient services, hospice@home, bereavement groups) coupled with our emic approach via unrestricted participation in away days, strategy days, and staff workshops, makes us uniquely advantaged in terms of our rich data. We are also fortunate that when tasked with examining EOLC through a management lens, we were given what MacInnis et al. (2020) call a boundary-breaking opportunity: to engage with understudied consumers (the dying and bereaved), using the relatively novel method of a rich extended case study (Burawoy, 1998), that has impact outside the academic management discipline. Indeed, our hospices have already begun to make extensive improvements to their services and, importantly, within their wider collaborative networks. Our work has also taken a non-traditional route to dissemination when we gave evidence at the all-party parliamentary group on EOLC at the UK Parliament as well as addressing a range of healthcare practitioners in various forums.

We did not set out to examine healthcare access. Rather, the original aim of our study was to give a voice to those transitioning to EOLC in order to improve services. As more hospices requested to join our study, and we immersed ourselves into the problems facing EOLC users and providers, our insights into the workings of EOLC services grew. Long recognized as an aspect of healthcare that has myriad barriers to access (Parajuli et al., 2020), we were struck by how many people who had actually managed to gain entry to EOLC services had endured delays, frustrations, and obstructions at every stage of their journeys. Not all made it to the benefit realization stage. We heard from bereaved families how, for some, entry to the system had come too late. Yet, from a policy perspective, they had gained access because they had gone through the referral process. We therefore began to challenge this perspective, and, in keeping

with the extended case study method (Burawoy, 1998), our multiple dialogues led us to novel exploration of our data and a new explanation of the empirical phenomena we beheld.

Of course, one has to stand on the shoulders of giants insofar as we cannot ignore what others have theorized before us. Thus, we fully acknowledge that Ribot and Peluso's shoulders are those on which we stand. Their 2003 redefinition of access to scare resources from a right to benefit to an ability to benefit sowed the seed that grew into our theoretical framework of healthcare access. However, our work is far from 'theory-enabled' which is when the researcher starts with a theory and searches for its application. Rather, our work presented here comprises discovery, making the leap from data via abductive reasoning to a new way of understanding healthcare access not in the traditional way of conceptualizing access as referral or ingress, but rather as the realization of benefit.

Theoretical Implications

Moving beyond ingress. Our proposed theoretical framework transforms the definition of healthcare access. For decades, policy and research has defined healthcare access as the availability of opportunities for entrance to a healthcare system (Aday & Andersen, 1974; Rader et al., 2020) and usage rates (Detollenaere et al., 2017; Zhao et al., 2020). Reconceptualizing healthcare access as the 'ability to realize health benefits' has several major advantages over previous definitions. First, it overcomes conceptual and methodological limitations inherent in earlier definitions (Dixon-Woods et al., 2006) that confine our understanding to availability and utilization. These are inadequate because availability does not always equate to levels of need, while measures of utilization do not consider benefits (Allin et al., 2007). A focus on realized benefit includes availability and utilization, while extending our understanding of what

healthcare access actually means. We suggest that by including the ability to benefit, we are incorporating the fundamental purpose of healthcare in our definition. Put simply, from our perspective, even if there is a clinic appointment available and a person takes that appointment and attends the clinic, unless they derive any benefit from the visit they have not accessed any healthcare.

Conceptualizing access from one of infrastructure and entry to one mediated by myriad and diverse contrivances that enable or hinder a person's ability to derive benefit immediately shifts our thinking from organizational factors to a focus on the people using the service. This perspective fits much better with the person-centered paradigm, reflective of the transition from disease focused to individual patient need, which healthcare systems across the world are striving to accomplish (Feder et al., 2020). While transformations to models of person-centered care are complex, lengthy, and in reality still in their initial stages, this large-scale cultural change requires examination of structures, processes, and habitus that impact patient experience (Bokhour et al., 2018). We suggest that a change to the way we define access to one that focuses on ability to derive healthcare benefits has the potential to be significant in helping to drive this profound philosophical shift.

Our new definition of access also broadens the consideration of healthcare benefits from disease modification towards holistic wellbeing. Current interpretations of access requirements, which focus on disease prevalence (Smith & Connolly, 2020) fail to consider the whole person. A focus on ability to derive benefits suggests the need to consider the person rather than a disease, and to take a wellbeing perspective that contemplates psychological and social benefits in addition to physical health. This is important if we are to move from a narrowly-defined

biomedical model which overlooks subjective interpretations of experience and treats patients as passive recipients of healthcare (Nettleton, 2021).

Finally, our new conceptualization enables examination of barriers to access not just for the excluded, but also for those who do gain entry to healthcare systems but then fail to receive benefit. Current frameworks assume that only those who fail to enter the healthcare system face barriers to access, classifying those that fail to gain entry as marginalized or excluded. This results in often poorly-defined reference groups acting as the comparison group for others, a practice that often relies on untested normative assumptions about need and capability levels, and which of course risks failing to uncover barriers faced by the reference group (Dixon Woods et al., 2006). In overcoming these drawbacks inherent in existing frameworks, our new theoretical model is more inclusive.

Novel analytical framework. Our theoretical model of benefit realization provides a fresh perspective from which to analyze healthcare access. The use of stages forces consideration of the person's whole healthcare journey. This is important because, as we have seen, many patients require referral to multiple clinicians within one journey to benefit realization. Existing frameworks, used to examine access to primary care, or access to oncology, for example, fail to consider the patient's holistic experience. Considering access from a single medical discipline limits our understanding from the patient's perspective and overlooks the interdependencies between providers. Our theoretical perspective views healthcare as comprising assorted interlocking multiple systems with local idiosyncrasies that help or hinder collaboration and coordination between them (Grudniewicz et al., 2018). Importantly, it is only from the patient's perspective and not the medical discipline's viewpoint that we can begin to understand these local features and the way they interlock. From a policy perspective, provision of services means

the right to healthcare access: it is only through in-depth analysis of the practical experiences of people that we can begin to understand how barriers restrict access in practice (Levesque et al., 2013). Appreciation of these practical features is crucial because, despite diffusion of complex systems thinking, there is a dearth of research into threats to patient safety that lie in the connections between providers (Waring et al., 2015).

Throughout the patient journey, the interrelated theoretical benefit assemblages provide researchers with a framework that enables depth and richness to healthcare access analyses. The assemblages recognize that receipt of healthcare is the outcome of myriad different processes and factors through which actors have to navigate, often requiring considerable effort on their part (Dixon-Woods et al., 2006). These actors are not limited solely to the user. Rather, the framework assists in examining barriers from the perspective of all relevant actors, which is important in spotlighting systematic obstacles for providers, too, in order to reveal areas where training, habitus, and resource issues need addressing. Examining healthcare access from this perspective therefore has the potential for real organizational change in healthcare services. Crucially, consideration of all relevant actors and their interactions also provide insights into collaboration between different healthcare providers, which is a novel perspective for healthcare access frameworks and is of importance because limiting our focus to supply and demand factors ignores the centrality of relationships and interactions (Macdonald et al., 2016).

Because our theoretical model of healthcare access moves from a focus on rights to a focus on ability to benefit, it lays bare the power imbalances inherent within the service. From this perspective, healthcare access occurs only when people have managed to transform their rights into their ability to actually benefit, and to do so they must comprehend relevant communications, navigate a complex and unfamiliar institution, and regain some agency. Some

people do not manage to achieve this. Hence, our framework helps to scrutinize the ways in which some manage to benefit, while at the same time spotlighting the reasons why others do not, laying open the underlying power forces that impact equity of outcomes (Gimelli et al., 2018). Indeed, while all three assemblages acknowledge that healthcare services are unique in their complexity, the agency assemblage in particular spotlights the emotionality and consequential feelings of vulnerability for users. Perhaps, then, this theoretical model has the potential to kick-start social change (Ribot & Peluso, 2003). Certainly, we suggest our framework presents a more critical approach which honors the user above medicine, and questions the status of healthcare providers (Nettleton, 2021).

Generalizability. Though our theoretical model emerged from our immersion with EOLC, we suggest it is useful to examine access to any healthcare service. Recent studies into referral to cardiology (Walton et al., 2018) and radiation oncology (Chierchini et al., 2019), for example, both uncovered some individual elements that are strikingly similar to a number of the EOLC contrivances we identified in our study. Our framework is more extensive than those used in these studies, and the potential for its use is apparent. Many of the individual elements we identified as important in EOLC are likely to be generalizable to other healthcare services. Health literacy, for example, is likely to be an access barrier to many different types of healthcare, simply because, unintentionally, the standard of much health literature is too high for a lot of people to fully understand (Hickey et al., 2018; NHS, 2021b). Even the issue of taboo, noteworthy in our research due to the prevalence of cultural prejudices to openly discussing the subject of death (EIU, 2015), is likely to be a barrier to access to services in mental health and programs for 'personal' issues such as bowel or bladder cancer or prostrate problems. Certainly, issues such as institutional logics and medical institutional arrangements (Levesque et al., 2013;

Waring et al., 2015) are likely to also be significant factors across a range of healthcare services. Moreover, it is plausible that the framework has applicability outside mainstream healthcare into wider care services such as various social care services where systems are complex and users are vulnerable.

Practical Implications

While we have to date worked with our collaborating organizations on service design innovations and changes to various institutional arrangements, in terms of sharing our work on access we have not yet touched the tip of the iceberg. Yet in the work we have shared we have already met resistance from a minority of clinicians, as is expected when conducing boundary-breaking research (MacInnis et al., 2020). Nevertheless, we believe that viewing access to healthcare as benefit realization is a step towards embedding person-centered care into healthcare systems and ultimately enhancing wellbeing for users and society as a whole.

Many of our findings have implications specific to EOLC - clearly, the benefit communications pertaining to EOLC need an overhaul, for example. However, what is striking is in most cases we found that actual EOLC services were person-centered, actors find ways to collaborate effectively, and EOLC services do provide clear and important benefits. Our case study reveals that in actuality embedded within primary and acute healthcare services are the many barriers to ingress into EOLC. Ironically, then, we suggest that our theoretical model, developed in EOLC, is actually more relevant to primary and acute care providers. From a practical perspective, the framework is not difficult to use. It is possible to conduct an analysis of the patient journey to benefit realization for any medical specialism within any aspect of a healthcare service. Managers could use the framework in phases, concentrating for example on

examining the underlying reasons for delays at one journey stage in particular, or scrutinizing one specific benefit assemblage at a time.

Finally, the theoretical framework has policy and social implications. Taking our unique view of healthcare access overcomes the problems inherent in the employment of utilization rates as a proxy for access (Detollenaere et al., 2017; Rader et al., 2020; Zhao et al., 2020). In turn, it has the potential to shift thinking away from access requirements that focus on disease (Smith & Connolly, 2020) towards the individual, many of whom will present with comorbidities (Etkind et al., 2017). Currently, failure to contemplate multiple disease results in suboptimal care (Petrosyan et al., 2020). Finally, by better understanding the barriers to benefit realization even among those who do manage to enter healthcare systems, we can begin to identify the very real hurdles that the marginalized and disadvantaged do not manage to overcome. Hence, the framework has the potential to contribute to a more equitable world.

CONCLUSIONS

The importance of access to healthcare is undisputed, yet large numbers of people across the globe fail to access the healthcare they need. In this paper, we argued that the ways in which both policy and popular research frameworks conceptualize healthcare access fall short of reflecting what healthcare access actually means. Based on an extensive piece of research into EOLC, and incorporating multimethod mixed methods, we proffered a theoretical framework of healthcare access. The model conceptualizes access not as a right to use or as an opportunity to use, but as the ability to realize benefit. Hence, we argue that even if a person manages to navigate referral into a healthcare system, unless they derive benefit from it they have not actually accessed any healthcare. Our model posits that healthcare service users need to navigate

a journey comprising need recognition, acknowledgement, ingress, and finally benefit realization. Throughout this journey, there are three interrelated theoretical assemblages, within which lie myriad contrivances that enable or obstruct the journey to benefit realization. We have called these theoretical assemblages communications, institutional characteristics, and agency. The model extends traditional definitions of healthcare access, provides a structure that enriches access analyses, and provides a framework that is of practical value. Hopefully, in using the framework, researchers and practitioners can uncover hitherto hidden barriers, which in turn improves benefit realization in healthcare and therefore enhances wellbeing, ultimately creating a better world.

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Figure 1.

Theoretical Framework for Healthcare Access: The Journey to Benefit Realization

Journey →	Need Recognition	Acknowledgement	Ingress	Benefit Realization
Communications	Realm of Understanding	Timing	Gatekeeper Dialogue	Clarity
Institutional Characteristics	Provider Training	Institutional Logics	Institutional Arrangements	Person-Centred Care
Agency	Power Imbalance	Fear	Proxy Agency	Collaboration