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Pathways to care - how Superdiversity shapes the need for navigational assistance

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ABSTRACT

The recently developed sociological concept of superdiversity provides a potentially interesting and useful way of developing an understanding of life in contemporary Europe. Here we report on research based on individual narratives about access to healthcare, as described by a range of people from very different socio-cultural backgrounds in four European countries. This paper notes the frequent appearance in first person narratives of the need for navigational assistance in the form of knowledge, cultural competence and orientation that facilitate the identification and use of pathways to healthcare. Our dataset of 24 semi-structured interviews suggests that, in the context of needing healthcare, the feeling of being a 'stranger in a strange land' is common across a wide range of backgrounds. In social settings characterised by transnationalism and cultural heterogeneity, understanding the need for navigational assistance, particularly at times of uncertainty, has potential importance for the design and delivery of health services. The relationship between the inhabitants of contemporary Europe and the healthcare systems available in the places they live is dominated by both complexity and contingency – and this is the cultural field in which navigation operates. (187 words)

Key words: navigation; pathways to healthcare; Europe; diversity; migrants

Introduction

It has long been recognised that, when a person seeks medical attention, their decisions and actions often involve collaboration with others and use of lay referral networks (Cornford and Cornford 1999). These interactions can involve a wide range of people, a selection of sources and a broad spectrum of functions. For example a person may want to talk over their symptoms with a friend or family member to see if they recommend any particular route to follow, treatment to try or therapist to contact (Cornford and Cornford 1999, Cook-Craig 2012). Such conversations may be key to the illness experience of people with cancer (Illingworth et al 2010) and recourse to lay referral networks is often a precursor or a substitute to consulting a health professional (Garro 1986). It was for example a key part of the decision-making process of rural African-American men about whether to attend screening for prostate cancer (Jones et al 2010). In a more formal

context a patient at a medical facility may opt to use the services of an interpreter or advocate. Any pathway or journey to (and through) diagnosis and therapy is, indeed, highly likely to include some kind of discussion, advice, orientation or help from others. In this paper we suggest that this aspect of access to health care can be conceptualised as a process akin to finding the route for a journey and that the help that people acquire from others is, essentially, assistance with navigation. This paper explores this navigation process by analyzing narratives of health-care seeking pathways in order to map personalised, individual accounts of experience onto the complex landscape of social, ethnic, economic and cultural differentiation observable in contemporary Europe.

The idea of placing healthcare-seeking (or help-seeking) behaviour at the centre of data collection and analysis has a long history in the social scientific approaches to healthcare systems (see, for example, Kasl and Cobb 1966, Igun 1979). Although the idea grew initially from studies of mental health and psychiatric medicine among minority groups, it has been shown to be a particularly useful theoretical grounding for developing understanding of how individuals construct their personal participation in culturally complex healthcare environments (Ahmad 1993, Culley 1996, Facione & Dodd 1995, Green et al. 2006). In our study, the 'healthcare-seeking journey' is the essential theoretical framework within which the collection and analysis of individual narratives is sited (Rogler and Cortes 1993). By mapping the decisions, perceptions, actions and evaluations inherent in individual accounts, we aim to construct a clear picture of the social and cultural realities of the search for healthcare in four European countries, from the unique perspective of the service-user.

The study is set within the concept of 'superdiversity' (Vertovec 2007, Phillimore 2011) and the framework of theories of intersectionality (Anthias 2005), which present useful opportunities for understanding the politics of belonging in contemporary Europe without falling into essentialist categories. Theories of intersectionality emerged as a reflection of

the critique by Black feminists that existing theories of gender and class neglected issues of race (Davis 2008). By pointing to the importance of intergroup differentiation (Crenshaw 1994), they provide a framework to conceptualise social stratification in a different way. The location of each individual is thought of as emerging from multiple variables which can have cumulative effects. Superdiversity is a term used to describe the increasing complexity of migration-related ethnic diversity and of social stratification (Vertovec 2007). The concept transcends previous theories of multiculturalism, in that it recognises a level of socio-economic-legal complexity distinguished by a dynamic interplay of many variables including country of origin (comprising a variety of possible variations such as ethnicity, language, religious tradition, regional and local identities etc.), migration experience (often strongly related to gender, age, education, social networks, particular economic niches) and legal status (implying a wide variety of entitlements and restrictions). This emphasis on multiple variables is where superdiversity meets theories of intersectionality. Superdiversity has arisen due to a global shift in migration patterns in Europe whereby the pattern in the 1950s-70s in which large numbers of migrants from a few places settled in a few places has been gradually replaced since the 1980s onwards by small numbers of migrants from many places settling in many places. Processes of socio-cultural diversification include not only migrants who bring different languages and variegated understandings of health care and healing, but also the heterogenisation of values and norms within the settled population. Such reconfigurations pose a challenge for European health care systems caring for an increasingly diverse population with ever-shrinking resources.

Method

The study was carried out in four countries in Western Europe (Sweden, Germany, England and Spain) all of which have seen increasing ethnic heterogeneity in their populations along the lines of 'superdiversity' described above. Each of the selected countries represents a different model of welfare and there are differences in the

organisation and funding of health care as well as access to it (see Kaiser Permanente 2010).

We aimed to produce meaningful comparative experiential data across a range of diverse settings and groups. In order to achieve a contextualized understanding of how and why social conditions shape health, a narrative approach was selected as, “Narratives provide an analytic opportunity for exploring the links between structure and experience and between explanation and action” Williams (2004:289). We collected accounts of pathways to healthcare by asking participants: How is it that you came here? Have you or any of your family/your household needed or used any health services recently? What is the most serious health problem you (your family/household) have ever had? This relatively loose structure enabled the participant to select those stories which they felt to be significant either to themselves or that they perceived would be of interest to the interviewer. It also helped us to situate the personal and biographical stories within the social, economic, political and cultural context from which they emanated. Narrative interviewing often focuses on the highs and lows of lived experience (Gergen 1994) and we followed this by asking specifically about health seeking behaviour for the most serious health problem that had been experienced. We viewed these stories as what Denzin has termed “messy texts” which focus on “those events, narratives and stories people tell one another as they attempt to make sense of the epiphanies or existential turning point moments in their lives” (Denzin 1997: xvii).

Ethical permission from the relevant University committee was obtained. Given the exploratory nature of the study, we decided at the outset to recruit a highly diverse and relatively small sample. In order to recruit a heterogeneous sample, our starting point for recruitment was not pre-defined communities, but specific neighbourhoods (both urban and rural) in each country in order to include people from a wide variety of backgrounds. We used purposive sampling to ensure rich diversity in the composition of the sample in

each country in terms of age, gender, ethnic and linguistic backgrounds and to ensure inclusion of participants from the majority population too. In Sweden all but one of the participants lived in a city with a relatively diverse population and the sixth participant lived in a neighbouring municipality, a town of about 7,000 inhabitants which is sometimes referred to as 'super-Swedish', because it has a lower proportion of immigrants or people of foreign background, compared to the larger neighbouring city. In Germany two participants lived in a middle sized University town, with considerable numbers of international students and academics, but with a predominantly white population. These interviews were contrasted by three participants who lived in a neighbourhood of a regional capital with high numbers of working class migrants (former so called guest workers). The sixth participant lived in a village but was not born there. In England participants were recruited from a densely populated urban neighbourhood in South London well known for its ethnically and culturally diverse population and also from a rural district which lies on England's east coast with a predominantly white English population most of whom have family roots in the immediate area. The neighbourhoods in Spain included a rural coastal area whose population includes retired North Europeans and (mainly African) rural workers and multicultural areas of two cities in the South of Spain. We recruited people through a number of organisations and networks including an adult language class in Sweden, an ethnic diversity outreach service in rural England, a solidarity organisation in Spain and through contacts from previous research in Germany. Friendship networks and snowballing were also used to make contact with participants in all countries.

One-off face-to-face audio-recorded interviews were conducted in participants' homes either in the official language of the country, the native language of the participant, or in English. Each interview took between 30 minutes and 2 hours. The interviews were conducted by the authors of this paper without the need for interpreters as all authors are fluent in English and the language in which the interview was conducted. Due to the

heterogeneity of the sample we were not expecting to reach data saturation. Rather, we were aiming to see whether meaningful narrative commonalities emerged. The interviews were initially analysed by the researchers in each individual country using standard thematic analysis. Having independently identified key themes in the data for each country individually, the interviews were then shared across the research team prior to taking part in an intensive two-day analysis workshop. At the workshop, the individual interviews and the themes identified for each country were discussed at length with a focus on identifying commonalities and differences across the dataset within the context of the varied health care systems in each of the four countries. This included extensive discussion about key themes and contradictory data as well as a critical examination of potential bias and influence of the researchers in each setting.

Sample demographics

Table 1 provides details of the diversity of participants included in each of the four countries. In each country men and women of different ages, ethnicity and migration history were included. Even where there were apparent similarities this often masked differences. For example, one of the white German women born in Germany was a converted Muslim and drew upon religious networks for health support.

Table 1. Sample demographics

| | England | Germany | Spain | Sweden |
|---|---|---|---|---|
| Gender | 1 male 5 female | 2 male 4 female | 4 male 2 female | 3 male 3 female |
| Age range | 28-73 | 38-56 | 22-73 | 18-51 |
| Place of origin and years of residence in country where interviewed | England* AngloAlgeria* Anglo/Jamaica* Jamaica(45+y) India (45y) USA (3y) | Peru (19y) Ghana (12y) Germany* India (2y) Germany* Germany* | Scotland (10+y) Romania (15y) Switzerland (10y) Latvia (8y) Mauritania (12y) Latvia/Russia (10y) | Pakistan (2y) Holland (3y) Somalia (<1y) USA (<1y) Sweden/Finn* France (12y) |

* = born in country where interviewed

(y) = number of years living in country where interview took place

The Swedish sample included only one-Swedish-born participant and four of the other five had migrated within the last three years. Only two spoke fluent Swedish. In Germany three of the participants were German born, two had lived there for over twelve years and one for only two years. Of the three non-native Germans, only one spoke functional German. In England, three of the participants were born in England, two were very long-standing migrants and one had lived there for three years. All except one were native English speakers and the sixth participant spoke fluent English. The Spanish participants were all migrants although one had lived there since childhood and the others were also relatively long-standing residents having lived there between eight and fifteen years. All spoke fluent or functional Spanish.

The sample was mixed in terms of income and qualifications with about half being well-educated and economically comfortable and half having few qualifications and a relatively low income. At one end of the spectrum there was a recently arrived eighteen year old Somali refugee seeking asylum and, at the other end, a wealthy Swiss businessman who had retired to Spain for lifestyle reasons. Across all sites, only one participant was in an 'illegal' position at the point in time of the interview, although the sample included four others (two in Germany, one in Spain and one in Sweden) who either lacked the legal status or the requisite health insurance to access health care when they first migrated.

Due to the use of snowball sampling, some of the participants were known to each other. The German sample included a married couple, while three of the English participants had a friend in common and the Spanish sample included a triad of two friends and one of their lodgers. Three of the Swedish sample had children at the same school, but didn't know each other.

Results

Despite the diversity of the sample and differences between the four health care systems, parallels emerged in the stories that were collected, particularly in accounts of seeking healthcare in critical situations. In a number of accounts in each site, the need for help with navigation and the fulfillment of that need were significant aspects of the narratives collected. In the texts, navigational assistance appeared as advice on a range of symptoms, ailments, therapies and treatment locations, facilitation with access to care (including making contact with services, companionship and transport), financial/material help, linguistic and conceptual assistance to access and engage with health care at critical moments. These navigational roles appear repeatedly in the interview texts, and in many guises.

Who provides navigational assistance?

The navigation function can be supplied by an organisation, such as a charity providing support to vulnerable migrants or a church for those with a strong religious affiliation. For example, a Muslim couple in Germany (G2 a Ghanaian and G4 his German wife), contacts from the Mosque were important, in particular for advice on how to get a 'Kur treatment' at a health resort (which under certain circumstances is covered by health insurance), as well as on alternative and spiritual treatment and on doctors and homoeopaths.

Many participants used the internet as a navigation tool to seek advice about pathways through the system or to find alternatives if what was wanted was not available from the local health care system. For example, an American in her late 40s living in England (E6) used the internet to access her preferred medication, which she had used when living in the United States (US), to treat her thyroid condition as it was not on the approved list and therefore inaccessible via the English NHS. Similarly, a participant in Germany used the internet to identify the nearest paediatrician when they moved to a new city.

In the narratives collected during fieldwork, however, the most common source of navigational assistance was another person acting as an individual, rather than as the

member or representative of a specific organisation. In our interview material, we have found that the personal suppliers of a wide range of navigation functions were found within one of three social circles: they were members of family (spouse, parent or child); they were located in friendship/neighbourhood networks; or they were individual health professionals or people with a specific connection with the world of health care.

Spouses played a key navigational role particularly those that were from the majority population or were long-standing residents and therefore familiar with the local health care system. Participants who were migrants with native or longstanding resident partners (Sw2, Sw6, G2, G3, E6, Sp4, Sp6,) regularly consulted their partners about how and when to access care. Interviews with parents of young children showed that a key preoccupation was with navigating the system on behalf of one's offspring and there were examples of this continuing to adulthood as in the case of the young English mother (E1) born and living in South London who involved her mother who lived close by in making and executing decisions about whether and when to seek emergency care for both herself and her children. Friends and neighbours also helped participants to navigate the system as in the case of the new mother from Latvia living in Spain who, when her baby developed breathing problems, rushed to a neighbour who called for emergency care. Once in the health care system, then navigation was often transferred to the health professional.

Many of our participants talked about being the supplier of navigational assistance, as well as being someone who needed and used such assistance at some times in their lives.

Suppliers of the navigational role often shared the following characteristics: having experience of health care; having knowledge about health (e.g. health professional training or self-acquired expertise); having knowledge of the health care system in the immediate locality; being relatively well educated; being relatively culturally competent (for example functionally fluent in the local language used by healthcare providers and knowledgeable about local behavioural norms); having access to communications technology such as

telephone or a good internet connection.

Navigational roles

The range of navigational roles which a person (or indeed an organisation) may supply are well illustrated by Sp1, a Scottish man, who retired to south of Spain with his wife over ten years ago. He had acquired good working Spanish which, together with his understanding of the structure of the health care system, as well as local expectations and entitlements, he employed when helping other foreign residents navigate their way through the Spanish health care system.

In the first example, he talked about how he helped a fellow British resident in Spain with communication when visiting a local doctor:

So this particular chap who has got massive heart problems who I've been helping for three or four years ... went to the local doctor ... he ... says 'I've been told it's the end,' ... 'the doctor says there's no more that can be done'. So I just contacted the doctor and said 'look, so and so said this' and he [the doctor] said 'no, I said [to the patient] there's no more I can do for you as a general practitioner, I will make an appointment for him to go see a specialist'.

In this example, his linguistic competence enabled him to provide reassurance to the patient that *'the end'* to which the doctor referred was not heralding imminent death, but simply the limit of what the general practitioner could offer and hence a referral to secondary care.

The navigational function may go far beyond assistance with communication and language and often utilized sophisticated cultural competence and understanding of the local health care system to help to circumnavigate complex health care systems. In this second example from Sp1, he explained how he used his knowledge of the system to help a friend get

treatment despite lacking the requisite papers and then subsequently to circumvent the financial bureaucracy of the Spanish system of payment:

Sp1: Another chap who got into a difficult situation where he got a chest condition ... So I took him to [the hospital] ... the doctor said ... 'you should take him back to Britain' because he didn't have his E111 [the health insurance card used at the time by British citizens seeking healthcare in Europe]. And I said 'no I can't, he's dying' ... she called up and got him in through the back door and then we registered the next day. ... an incredible service they gave him ... then he said 'I feel much better' ...says 'now I've got a bill for 3,500 quid' because he'd lost his E111 ... so I went with him into the accounts department at [the hospital] and I said 'he's late, he's now got his new one, here it is', I said 'look he can't afford it [is there] any chance?' [mimed ripping up a piece of paper].

Int: They ripped it up?

Sp1: That's right so that's not going to happen if you don't know the system.

The third example of Sp1 providing navigational assistance came from the interview with Sp2, his Romanian lodger, who had been living in Spain without any legal documents for 15 years. Sp2 talked of his experience following a road traffic accident where his need for care had been compromised by his fear of being discovered to be an illegal immigrant.

Then, two years ago I had an accident - a road accident - just near here A car ... knocked me off my bike. I broke my hand and lost two teeth. Because I didn't have the right to any health attention, I did nothing for five or six weeks. At that point, 'Señor G' [Sp1, the British friend he now lives with] took me to... a private clinic - where you have to pay. I saw a German doctor - a very very good doctor. And they don't care about documents or if you're legal or if you have social security or anything. So they sent me for an x ray at a private centre ... and I paid.

(translated from Spanish)

This story illustrates the vulnerability of those who do not have access to statutory health care. Following the accident, Sp2 would not permit passers-by to phone an ambulance to take him to hospital, due to his concern about his lack of legal documentation. Eventually, due to persistent pain in his hand, Sp1 persuaded him to seek care and he was wholly reliant on this assistance both to access care and to avoid detection as an illegal migrant. There were however, limits to the support as Sp2 declined the operation that the private doctor recommended following an x-ray as he could not afford it and has lived with chronic pain thereafter, saying *“I take Ibuprofen [painkiller] every night”*.

Need for navigational assistance

Those who had most recently migrated and in particular those without legal rights to access care were most in need of assistance. A Ghanaian man (G2) who, prior to the interview did not have sufficient funds to be covered by his German wife's private insurance scheme, 'borrowed' an insurance card from another African man he knew in an emergency situation (a deep cut, which needed stitches), echoing the creative use of documents described in other contexts (Anderson and Ruhs 2008). And a migrant from Peru (G3) sought help from his German partner when he had a large hospital bill, to re-claim the cost from social services. However, what was striking in the interviews was that the need for a navigational support was not confined to the newly migrated or the disenfranchised. Such assistance was required by all of those who encountered an aspect of the health care system with which they were unfamiliar or in unexpected situations such as accidents or severe acute illness.

A striking example of getting support with navigation was from a 41 year old Swedish women born and raised in Sweden (Sw5). She had had three serious cancer diagnoses, and following diagnosis of breast cancer, she described the breast cancer nurses as 'fantastic' interpreters and facilitators. Whilst she was receiving chemotherapy the nurses provided 24

hour mobile phone access for information and support. She described them as like 'a spider on a web' (*'spindel i nätet'*), pulling in her test results from across the hospital and interpreting their meaning for her.

*The breast cancer nurses were **so** fantastic. They are the **most** wonderful in the whole world... it is wonderful that they exist.*

(translated from Swedish)

As she progressed from chemotherapy to radiotherapy, Sw5 described in some detail how in the process of being transferred from one section of the hospital system to another the "fantastic" closely attentive and supportive role of the nurses, was lost. She went on to talk about the need for an advocate to help get the best deal from the complex Swedish welfare system: child benefit, sickness benefit, paid parental leave etc are all allocated according to particular rules which even well-educated Swedes find hard to follow.

Sw5's insistence that everyone needed help in negotiating their way through health care systems, was echoed by an English participant (E3), a London-born man aged 40 who had been raised by his single father from Jamaica. He was educated to degree level and worked in a professional occupation, and described how he provided support to his father who "*never moaned about pain*", when he uncharacteristically started to complain of backache. He persuaded his father to seek treatment and, when he did so, was told it was nothing serious. The pain persisted and he again persuaded his father to go the doctor and again they said "*it was nothing serious*". At this point, E3, who was living overseas at the time, intervened and spoke directly to the care provider.

E3: I said, 'Look, my dad is not going to be moaning to me, how many miles away, about breathing problems'. I said, 'I need a second opinion', ... I kept coming back, ... and someone eventually did check him properly ...

Int: And you sound as if you were actually pretty persistent.

E3: Yes. You know, the thing was, I think ... I feel as though my dad was [dismissed as] ... 'He's an old black man' ... they were batting him off on his own, and I persisted and persisted and persisted ... they basically tried to brush me aside, but with my persistence, ... they maybe thought about it, and said, 'Okay'.

As a result of his persistence E3's father was referred for tests and subsequently diagnosed with lung cancer.

Of course, there were many examples of confident self-navigation of the health care system among both long term residents and those more recently arrived in each country. A born and raised South London woman (E1), who attended the same primary health care centre she had used as a child, knew all the doctors well and explained how she 'played the system' to get what she wanted.

I know which one to see for what I want. I can play them you know, if I'm worried I can go to Dr H because she always errs on the side of caution.

Similarly, a German born woman, who spoke at length about how the health provision in her village had changed negatively, had developed tactics to get access to the expensive diagnostic technology she preferred. Likewise, Sp6, a Latvian lawyer married to a Spanish man and living in Spain, was clear about the type of complaints she was happy to take to the statutory Spanish health care system and those for which she preferred to seek private care. A retired nurse-midwife from Jamaica (E4), living in a small town in England, described self-testing her urine to diagnose diabetes (a condition affecting many of her family of origin), prior to presenting to the doctor. And among the recent immigrants (Sw1, 2 and 4, E6), there was evidence of confident self-navigation of the health care system, drawing on international experience elsewhere. One of the Swedish participants (Sw4) who migrated from the US

with a cancer diagnosis had already negotiated the continuation of her specialist care through her US consultant prior to her migration. In terms of navigation, her support mainly came through doctors: her doctor in the US put her in contact with the specialists in her cancer in Sweden and she arranged the transfer of her treatment via email and phone calls.

However, a number of participants needed to call on navigational support in their pathway through healthcare and, what was most striking was that this was not restricted to those without legal documentation or those who had recently arrived. After an accident in which her spine was injured, a German single mother (G6), who was still living in the city where she was born, needed a spinal operation and rehabilitation in an orthopedic clinic. Faced with intense pain and immobility, she found it almost impossible to understand her entitlements and to organise care for her child when she was hospitalised. She realised that she did not have adequate social networks and felt that working her way through the system of entitlements was a job in itself, in particular during a period of extreme bodily and mental insecurity having just experienced an accident and the threat of becoming partly paralysed. She was especially overwhelmed with the paper work related to her treatment:

The procedures are not comprehensible. That was specifically after the operation. I had the feeling ... I could have needed a secretary. That was such an amount of correspondence to do. I had to communicate with four different places and that was unbelievable ... To be able to keep it all together ... Had I sent this paper already? And in such a burdened situation, I found that incredible ... Everybody in the system is pushing it to the next person ... eventually it all ended up on my plate (translated from German).

The example of G6 shows that, even a well-educated woman with full entitlements who is a native speaker can, at times, find it difficult to navigate the system. The problem here was not so much getting access to immediate health provision or rehabilitative care, but rather to

identify the specific responsibilities and authorities of health institutions and insurance organisations and to administer the necessary correspondence and communication in order to get full access to her entitlements.

Thus, anyone can need navigational assistance, particularly in emergency situations, but certain people are more likely to need one. Among our participants, the Romanian man without documents (Sp2) in Spain relied almost entirely on a friend to obtain the care he needed in the pathway he described, as did the Ghanaian migrant in Germany (G2), who could not read or write. At the other end of the socio-economic spectrum of foreign migrants to Southern Spain, the retired Swiss businessman (Sp3) had purchased comprehensive health care insurance for himself and his wife. He had also acquired fluency in Spanish, and his narrative shows that he felt little or no need for navigational assistance or support.

Discussion

Healthcare navigation at times of uncertainty

The variable need for help and support in the face of life's vicissitudes, along with variation in the ability to offer such support, has been explored in various contexts and employing a range of metaphors (e.g. Frank 1995, Kleinmann 2006). Crises around disease or accidental injury involve social relations that have been analysed as therapeutic networks (Cataldo 2003, Krause 2008), as forms of social capital (Williams 1995) and, as networks, which encompass the agency of people and objects alike (e.g. Prout 1996, Timmermans and Berg 2003). A potential disadvantage of conceptualising the social relations of illness as a network is the risk of reifying a series of linkages that might or might not have any genuine bearing at the moment of crisis. Social capital has been explored to evaluate what social networks can do for people at times of illness, which seeks to demonstrate differential abilities to mobilise support according to social status (Portes 1995). Actor network theory has foregrounded the role of objects and, in our interviews material telephones, appointment systems and the internet played important roles: how seekers of healthcare employ digital

technology, particularly in order to access help and support across national boundaries would be worth exploring.

Missing from the network metaphors is the role of happenstance and the iteration of sequences of uncertainty in the process of seeking healthcare: sometimes crucial support will come from a trusted and longstanding friend (Sp2) or close family member (E3); at other times the support will come from a professional whose role is explicitly to provide such help (Sw5). However, in telling the whole story of an incident of healthcare need, a complex combination of different social, material and economic resources are deployed in contingent ways. Furthermore, our material indicates that seekers of healthcare are not in possession of a chart or map, through which a 'pathway' can be accurately mapped. Hence our use of the metaphor of navigation, particularly if envisaged in historic marine terms, offers a sense that healthcare seekers are in uncharted territory that is, by its nature, unpredictable (Vigh 2009).

Our stories were gathered in four distinct health and welfare systems and some specific features of the national health system were distinguishable in the interview material such as the base-level entry requirement (an insurance card in Germany or a personal identification number in Sweden). All the English participants reported a sense of economic security in relation to health care reflecting the fact that the long-established NHS has always been free at point of delivery. However, few features of the system were distinguishable in the interview material, suggesting that there are more similarities than differences between the four systems and/or that the nature of the health problem may be of greater importance than the context health care system in shaping narratives. We found a sense of expectation about services, often developed in another national and cultural setting, being read onto the current situation, palimpsest-style. In the moment of illness or injury, navigational assistance to chart a general direction, feature in our narrative material, however, there was little sense that this resulted in finding the 'correct', straight pathway through the available healthcare

resources. Rather the narrative continues to lurch along, towards (it is hoped) recovery, but with ongoing uncertainty. Furthermore there is very little sense that during episodes of healthcare-need, people had learned the structure of their local healthcare system, which is the implied aim of much health education material aimed at newly arrived immigrants. Rather, people learned limited strategies for meeting immediate needs, without necessarily expecting that these would work in the future or with different health problems.

There have been attempts to provide the navigational role organisationally particularly in North America in the field of chronic illness (Canadian Breast Cancer Initiative 2002, Esperat et al. 2012, Till 2003). There is a US advocacy service called the 'Patient Navigator', which "is dedicated to working with patients and families as they journey through illness and aging" (<http://www.patientnavigator.com/>). These schemes often target marginalised groups such as provision of advocacy to native American Indian women (Burhansstipanov et al. 1998) and in Washington DC a patient navigator connects those testing HIV positive in emergency settings with medical care (<http://www.guardian.co.uk/society/2012/jul/09/aids-conference-washington-dc-epidemic?INTCMP=SRCH>). Patient navigation in low income neighbourhoods of New York City is used to improve earlier detection rates of cancer (Freeman 2006) and the potential for peer navigation in a breast cancer internet support group has been explored (Till 2003).

Our study would suggest that formalised navigational support would indeed be useful in a number of settings to assist access to health care for particular groups in western Europe. This would include people at crisis points during chronic illness (eg. at the time of diagnosis, relapse, progression to a new stage or type of treatment). Such support may already exist, eg. specialist nurses for specific conditions, but are not a routinely and easily available aspect of the health care system in any of the four countries in which our study took place. Formalised navigational support could also be targeted at particular groups, e.g. recent migrants or other vulnerable groups. There is some evidence that such support exists,

primarily in third sector organisations, but provision is patchy. There is clearly scope for expansion and systematisation of such advocacy, buddying or other support schemes, whether voluntary or salaried, but, however comprehensive the provision, it will never completely replace the informal ways in which people seek direction in an uncertain world. No organisational initiative could ever anticipate the complex contingency of the ways that people's health problems intersect with other aspects of daily life, in terms of commitments to work, family, spiritual beliefs and pleasure. The difficulty of anticipating people's needs does not imply that healthcare systems should simply rely on lay referral networks to facilitate access to care. The tendency for healthcare professionals to expect patients to have an intimate understanding of the local healthcare system is also unreasonable, particularly in the context of superdiversity. The implications of our study are that healthcare systems need to remain open to patient referrals through a plurality of routes and be committed to understanding patients' in their own terms.

Superdiversity and navigational assistance

Complex formal systems are a common feature of European society and a need for help in health-related crises is evident across a diverse range of people. People use their agency in highly complex and contingent ways to use the care opportunities which exist locally. Moreover, the need to negotiate systematic restrictions to care is accomplished using a range of resources, and these commonly include using navigational assistance provided by an organisation or individual. It is possible to identify parallel disruptions between well-positioned people with ready resources and very vulnerable people who share fields of experiences in situations of crisis. Even the best-connected, well-resourced person can feel like a stranger in a strange land when encountering an unfamiliar part of the healthcare system. The difficulty of finding appropriate help crosses socio-demographic characteristics and, particularly in critical situations, navigational support may be required.

Our sample was very small in each country and barely touched upon the rich diversity of the European population. The English sample, for example, included only one new migrant, and that individual was a native English speaker and the whole sample in the four settings only included three new migrants. Furthermore many participants knew each other - reducing likely differences in experience. However, despite these limitations, the participants and their stories were sufficiently varied to enable us to develop our conceptual understanding of how conditions of superdiversity shape the need for navigational assistance

The transnational and narrative approach we adopted illustrates how individual actors experience and respond to the specifics of their own position in the context of their relationship with local society and how it relates to their position in the care system. During illness episodes people have to cope with their own experiences (which may include, of course, pain, discomfort and fear) at the same time as planning and carrying out what they feel to be appropriate behaviour in the context of their entitlement to care. Meeting and finding an accommodation with the views and perceptions of others (including institutionalised norms and restrictions) calls forth the need for navigational assistance. Our findings indicate that both the existence of this need, and the form and content of the assistance itself, are shaped by a range of attributes relating to the individual themselves and, more specifically, to their structural position in the local socio-cultural milieu. The “conditions of superdiversity” which, we suggest, shape the nature of navigational assistance in healthcare are set out in Table 2.

Table 2. The Conditions of Superdiversity which shape the need for Navigational Assistance

| FIELD OF DIVERSITY | SPECIFIC ISSUES SHAPING THE NEED FOR NAVIGATIONAL HELP |
|---------------------------|---|
|---------------------------|---|

| | |
|---|--|
| Official, Legal or Bureaucratic Situation | Legal status as resident Legal rights to employment/benefits Formal entitlement to healthcare services |
| Cultural Competency | Language skills (knowledge of /fluency in the local languages of healthcare) Literacy (specifically in the local languages of healthcare) Social status (perceived by self and perceived by others) Participation (and belief) in one or more medical traditions |
| Personal Identity and Circumstance | Native / Migrant (personal history in this context) Gender Sexuality Nature of family and friendship networks (relative conviviality or isolation) Beliefs in areas unassociated or tangentially related to health and illness (e.g. political views, religious affiliation) |

Within these fields of diversity, any individual experiences a unique combination of attributes, organised and understood as a personal history. And it is within the context of those conditions of superdiversity that navigational assistance is best understood. For example, the story of navigational assistance needed by the elderly Londoner of Caribbean origin (and supplied by his son in interview E3) was shaped largely by his socio-cultural status as perceived by him and elements of the local healthcare system (“... *I feel as though my dad was [dismissed as] ... ‘He’s an old black man’*”). In terms of shaping his needs, this aspect of his situation may or may not have been combined with language or literacy issues. His legal/bureaucratic status as far as residency and entitlement were concerned were not at all problematic. His family network included an educated and committed son who was willing and prepared to navigate and advocate on his behalf.

By contrast, the Romanian man (Sp2 described in his own narrative and also in that of his friend, Sp1) who needed care following an accident was in a very different legal/bureaucratic situation. While culturally competent in terms of language, literacy and negotiating local norms and social spaces, his legal status was that of undocumented foreigner. His entitlement to healthcare (both perceived by him and local providers) was essentially non-existent. His family network was fractured, largely geographically distant and functionally useless in terms of navigational help. His friendship network, on the other hand, was robust enough to successfully supply the assistance required.

Conclusion

Our study suggests that narrative methodology is a useful and productive way of exploring and deepening our understanding of access to healthcare in increasingly diverse European societies. We have found that the theoretical concept of 'superdiversity' has the potential to throw new light on how healthcare is sought and negotiated, particularly in terms of the assistance provided by others. Developing a better understanding of the processes of navigation is an important part of providing fair access to both public and private healthcare for all the different kinds of residents in a particular location. Our work has aimed to develop knowledge about the complex ways in which individual healthcare needs and access to appropriate care are shaped by the cultural, social, economic and legal contexts in which individuals and families find themselves. The details of navigational assistance in any one story are, of course, unique. Here we are putting forward an analytical structure that has the potential to develop an understanding of navigational processes at a more abstract level.

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