



## An Investigation into why People from Ethnic Minorities Seem not use Compassionate Communities Services as much as others at the UHCW NHS Trust

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### ABSTRACT

This service review sought to find out why Ethnic Minorities were under represented or not represented at all in the services that the chaplaincy department seeks to offer under Compassionate Communities (CoCo). Compassionate Communities is an initiative by the Chaplaincy Department at UHCW NHS Trust to extend the support services that Chaplains and Chaplaincy volunteers given to patients in terms pastoral care when they are inpatients in our hospitals and extend the same to them when they are in the community, especially those patients that have complex healthcare needs or have a terminal illness. From the current support groups run by CoCo like RIPPLE and TAB it was quite apparent that Ethnic Minorities were underrepresented. This Service Review (study) adopted the narrative as a method of data collection. The results from the narratives collected were never meant to be representative but just a survey of how the participants viewed the CoCo initiative. The findings show that the overwhelming majority of the participants did not know about the initiative except one that had seen a flier somewhere. Findings show that there need to rethink how such initiatives should publicised, it was also discovered that there in greater need to work with the researched community in order to find out what their real needs are as opposed to the 'perceived needs'. Related to issue of perceived needs, some interest groups felt that the services that CoCo offered were a duplication of services already offered in the community.

**Key Words:** Chaplaincy; Compassionate communities; Ethnic minorities; COVID-19 pandemic; Narratives; Health inequalities; Service review; Compassion; Spirituality; Faith; End of life

### INTRODUCTION

This paper seeks to use stories or narratives as a way of exploring the perceived lack of uptake of services by people from Ethnic minority community in the UHCW NHS Trust catchment area offered by Compassionate Communities. This investigation is not research on narratives per se, but a study that uses narratives as research tools to explore human experience [1]. This service review seeks to explore why there is not as much uptake of the Compassionate Communities provision by people from ethnic minorities. Knowing what services exist and how they function is important in informing the development of a more holistic approach to service delivery with a view to

enhancing collaboration between Compassionate Communities and local networks especially in the light of cuts to social services and the unavoidable impact of the COVID-19 pandemic and its disproportionate impact on the marginalised (Health Foundation Report, 2021) especially those in the ethnic minority groups.. This preliminary study discusses first, importance of stories or narratives as research tools used to try and understand how people respond or cope with bereavement or illness. A question that the readers might have is, why narratives were chosen as a method for data collection [2]. Succinctly sum up the essence of narratives or stories and how they capture the human experience when they point out that that "stories

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are about people's lives and being human". They go on to argue that stories "privilege the voices of the people studied". This means that participants become part and parcel of the unfolding epistemological and ontological reality as opposed to someone defining their reality through armchair research. Participants become core creators of the knowledge and understanding that is emanating from the research as their voices are the core part of the research outcome. Proponents of core creation such as Olson, et al., argue that it is vital to include the voices of the underrepresented groups if one is doing research about their needs. Therefore, collecting data through story telling is a natural method of enquiry for Chaplains, as this is how patients, (their relatives and staff the major groups of people we support) invite us into their lives through their stories as they explain their situation and how health problems have disrupted their 'normal life'. In order to tap into the rich narratives of people's lived experiences, Chaplains have to avail themselves to people in their time of need and this is what is called, "Presence Chaplaincy", a descriptor that was popularised by Holm (2009) [3]. Holm argues that Chaplains participate in core creation by completing the work that God started in creation by being present for the person in need, on God's behalf. Put simply, presence chaplaincy is support offered to people that are in need by reassuring them that "I am with you" if you need to speak or want someone to listen or share experiences with.

One advantage of availing oneself within the context of presence chaplaincy is that it is not considered 'face threatening' (in the sense of Brown and Levinson's 1978 Politeness theory) as other widely used data collection tools such as questionnaires and structured interviews tend to be. When using narratives to collect data, participants do not feel the pressure of data being squeezed from them; the process of data collection is more natural and less intrusive [4]. In terms of research methodologies, narrative slots neatly within the inductive research tradition, as it allows the researcher to collect 'rich data' beyond the limits of what they might have collected using a system that has finite and standard questions Glaser and Strauss. Inductive research allows the data an opportunity to 'speak for itself'.

When the research was commissioned, there was only one female chaplain from Ethnic minorities but now there are five female Chaplains in post, their knowledge of the community has presented us with a massive knowledge resource reservoir, compared to the time of inception of the Service Review. Having outlined a case for the use of narratives as a research tool, it is important to clarify what is meant by storytelling or narratives. Bamberg (2012) offers this comprehensive definition of a narrative.

When narrators tell a story, they give 'narrative form' to experience. They position characters in space and time and, in a very broad sense, give order to and make sense of what happened or what is imagined to have happened. Thus, it can be argued, that narratives attempt to explain or normalize what has occurred; they lay out why things are the way they are or have become the way they are. Narrative, therefore, can be said to provide a portal into two realms:

(i) The realm of experience, where speakers lay out how they as individuals experience certain events and confer their subjective meaning onto these experiences

(ii) The realm of narrative means (or devices) that are put to use in order to make (this) sense [1].

The idea of positioning relates to how people insert themselves into the record of their lived experiences as they tell their story. The stories are told from their point of view, in terms of how they experience the reality of living within the situation they are in, be it grief or the reality of living with complex health care needs for them or a loved one within the context of a bigger narrative about what is happening around them. Such an understanding of positioning aligns neatly with Sools (2012) [5]. Analytical frame of the 'small story' as a paradigm of the 'big story'. Sools (ibid) argues that 'the small story' which is the individual story, is happening at the same time as the 'big story' which is the unfolding of the bigger things in the wider world. The two are happening at the same time and they mutually influence each other.

To put this 'small story big story' paradigm into context, what is happening in the, UK, Europe or The World represents the interaction between the 'big story', for example, the COVID-19 pandemic and the small story that an individual presents as he/she positions him/herself through their narrative within the wider context on the basis of lived experiences. As such, the big story has an effect on what is happening in the lives of the individuals that are telling their small stories. This dynamic is most apparent in the way the Faith Leaders spoke and acted as 'gatekeepers' for their communities as they said they were aware of what was happening in the 'big story' as regards, cuts in social services, the politics surrounding the distribution of funds through the CCG for supporting communities ravaged by the COVID-19 Pandemic, Brexit and other social factors currently obtaining in the country. According to the faith leaders, these issues in the 'big story' have the net impact of exacerbating existing health inequalities as influenced by the politics of the day. Health Inequalities can be defined as:

...as the systematic, avoidable and unfair differences in health outcomes that can be observed between populations, between social groups within the same population or as a gradient across a population ranked by social position [6].

It has been observed that, Health Inequalities could be a contributing factor to why some members of the ethnic minorities did not want to participate in a study of this nature as they argue that academic investigations like this Service Review seem not to benefit them because of the 'perceived inaction' by authorities about well-known social, economic and structural inequalities that exist in our society.

Riessman commenting on the usefulness of narratives in diverse fields of study argues that: "Analysis of narrative is no longer the province of literary study alone; it has penetrated all the human sciences and practicing professions". In the context of this Service Evaluation or study, the personal story is being used to explore the intersection between personal stories and the big story with a view to understanding how individuals position themselves and their stories within the larger narrative as they try to cope with illness or adversity.

Narratives are therefore important in revealing how people position themselves vis-à-vis the 'big story' in ways that support "the commonly shared belief that who we are, or who we think

we are, is realized in the stories that we tell about ourselves; everyone not only has a story but also has a right to tell their story [1]. As such, it is important to hear individual stories of those affected rather than rely on the views of faith leaders from the ethnic community who did not recommend their members to participate in the current research, arguing that they know what the issues are for their communities.

## REVIEW OF SAMPLE AND SOCIAL CONSTRUCTION OF ILLNESS

Research participants were drawn from the black and Asian ethnic minority groups. In total 10 participants ended up being part of the sample on the basis of the referrals that came from an appeal that was sent through 'all users' emails sent to different staff and volunteer groups within the trust. Some of the participants were contacts of the main investigator, through his contacts in the community. The research had hoped to have a sample of around 20 participants experiencing grief or health problems. However, it was not possible to access the number of participants we hoped for.

Some of the participants that ended up as part of the sample were accessed through the snowballing method in which the first participant identified would connect researchers to the next person in similar circumstances. As a result of the challenges identified above, progress was slow, and we ended up reaching out to 10 participants only. However, the number of participants in qualitative research does not matter that much as long as the data gathered can reach saturation point. Glaser and Strauss saturation point can be loosely defined as a point where similar patterns begin to emerge in the data gathered. Data collected from participants was transcribed and analysed using the thematic analysis which puts emphasis on identifying, analysing and interpreting patterns of meaning within qualitative data [7].

Conrad and Barker (2010) explain illness from a social construction perspective, something that makes sense for this study as illness is best understood within the context of the society where the illness is being experienced [8]. Conrad and Barker (ibid) have defined social constructionism as, "a conceptual framework that emphasizes the cultural and historical aspects of phenomena widely thought as to be exclusively natural" (p.568). For example, being a cancer patient means different things depending on which part of the world one lives and the availability of healthcare provision in a particular geographic setting, or within the same country depending on whether one is poor or rich. The current effects of COVID-19 provided another case in point in terms of how Ethnic minorities and people that live in deprived areas were disproportionately affected [9]. People can be living in the same country or town yet have a very different experience of the same situation, condition or disease, therefore their social perception and experience of the same is very varied. Therefore the way they construct their reality around the same matter is very different.

A Social Constructionist perspective about disease and illness is premised on the conceptual distinction between "disease (the biological condition) and illness" (the social meaning of the condition) cited in Conrad and Barker [4]. In his view, "social constructionists emphasize how the meaning and experience

of illness is shaped by cultural and social systems". All the issues surrounding how different communities view complex health needs and their care, up to end of life is deeply embedded on which community the patient comes from and the medical as well as social networks that are available to the patient. One of the participants (JM10) was concerned about the way her community perceived her and her conditions and she had these questions. "I don't know how or why the whole community, like, Asian community they are not aware of it, that people can have fibromyalgia, they can have hyper mobility. To them because I am sort of a bigish lady, they're like you need to lose weight" [10]. At this level it does not matter what the condition is but how your community perceives you as a person living with a condition.

Linked to this social constructionist view of illness is the Foucauldian view of discourse. Foucault (1971) [11] believes that as human beings we are the product of the discourses that make us. The implications of this way of conceptualising the world (that discourses create us) is important when interrogating the nature of disease and how the patients living the experience talk about their experience of those conditions in the story that they create about ill health. The second part to this argument is that the reality of how these patients are cared for, and looked after in their community is based on how the community perceives them, and the discourse they use to talk of their illness.

## DISCUSSION

Participants involved in the research talked about their experiences in ways that showed that individuals living with a chronic illness get immersed in the life of dealing with the condition such that it alters their everyday experience of life [4]. One of the former Respiratory Consultants (Collin Guilder) in the UHCW NHS Trust, in a discussion with one of the Chaplains said he was trying to help, COPD patients "to live whilst they were dying, rather than die whilst they were living". He was in a quest to make the patients enjoy life in the midst of the course of living with chronic condition. Using the same logic, the way that a patient lives and conceptualises their condition influences how they handle the social scene around managing it. Conrad and Barker describe, "How the worlds of some individuals shrink when they are immersed in the day to day aspects of managing a chronic illness". This is true for the story told by JM1 who described how their lives (as a family) were revolving around the care for their father before he passed away. Here is what she said:

Before every meal we would take his blood sugar and then 90 minutes after, we took his blood pressure, monitored his weight so that we could see over a period of days or weeks how his weight was going up and down and whether that was reflected in oedema in his legs, his feet, around his abdomen and how that affected the shortness of breath. When people say "shortness of breath" you think what exactly does that mean for someone that always seems to be short of breath?

This quote shows that the lives of those caring for a loved one who is on End of life can intertwine with that of the patient to the extent that their lives revolve around caring for that loved one. This realisation for me shouts out that the befriending ser-

vices we offer as Compassionate Communities could come in handy even if it is allowing a family in similar circumstances to have just a two hour break.

This is what JM1 said about his Dad when he was well, she said; "...he loved to go out, one of the things he loved in the community was to go to lots of people's funerals of all the things he enjoyed. It was all about offering support to other people in their time of need". One thing that is apparent from the above is that for people of a certain age, supporting other people in the community is a source of pride and pleasure; they live for that sense of community.

The experience of illness therefore does not only alter the life of the patient but also those of the family caregivers as seen in narratives JM7 and JM6. The wife of JM7 says to the husband, "you do not know how it feels to look after someone all the time without a break". JM6 says this about sharing a single room with his brother, "it was very difficult and, he used to sleep on the bed and I used to sleep on the floor" In the case of JM7 there was disagreement on whether the family might need a befriender from Compassionate Communities to come to the house and offer a befriending service because the patient did not feel that it was necessary to have someone in the house to chat with, since the wife (who is the full time Carer), was always there. On the contrary, the wife felt that she needed somehow to come out of the whole situation and have a break from it all and 'breathe' as it is difficult to give 24 hour care to your spouse.

As far as JM6 was concerned, the extent of the impact of experiencing the illness was almost the same between brother (patient) and the sister (supporting and providing shelter for the brother). When there was only one bed between them, the sister gave up her bed to sleep on the floor, which shows the amount of empathy and close family bond within this family. I am convinced that you would not find close family relations and bonds such as this one in some families and in some communities.

This brings to the fore an argument that was presented in the focus group, that if you want to do research in the 'Asian' community, do not assume that you know what they need, you need to ask them what their needs are then create your research question around that, because as one of the chaplains put it, "one size fits all does not work with the Asian community". There is need therefore for a deliberate and conscious assessment of the needs of the targeted community, rather than presumption by the researcher.

One thing that is clear from stories JM3 to JM7 is that the consequence of living with the illness has not only radically changed the patients concerned, but also those close to them for example the spouse of JM7 is a case in point as well as the relations between daughter and grandchildren in JM5.

The depth of the knowledge Compassionate Communities will have in terms of understanding whom are we trying to support will be much fuller for the people who came through the Service Review as opposed to those referred by other agencies or departments in the hospital that only complete a form, given the uninterpersonal nature of a form as tool of collecting information [12]. This is borne out of the realisation that;

Narratives do not mirror, they refract the past. Imagination and strategic interests influence how storytellers choose to connect events and make them meaningful for others. Narratives are useful in research precisely because storytellers interpret the past rather than reproduce it as it was.

It is these connections between the past and the present that are critical in understanding how communities deal with health challenges and adversity and the role chaplaincy could play to alleviate suffering in ways that "help the patients to live whilst they are dying as opposed to die, whilst they are living" (Collin Guilder). Giving participants that opportunity to interpret the past in the context of their experience of poor health is a precious gift, as they can reflect on their healthcare provision.

The idea of involving communities in discussions about services and how they view them presented an opportunity that the participants really appreciated. For JM1 and her family they appreciated the opportunity to participate in the research as it served as a way to have family 'post-mortem' of emotions regarding the death of her father. The platform to talk about the death of their father (husband and granddad) was almost like a cathartic reflection and celebration of the life of a loved one.

Dad had grown up in East Africa and he'd never been back to Kenya, so he wanted to do that and the doctor had thought that it was best that we did take him as he might not be well enough to travel after that.

For JM5, the fact that she had an opportunity to tell her story really relaxed her and she was not only talking about her experience of ill health but also expressing how and why she came to live in this country. This is what she said:

When I came into this country (UK) in 2005, I came for my daughter who was about to give birth, she had a difficult relationship with the husband and asked me to come and help, she gave birth when I was in this country already, after giving birth, they reconciled with the husband.

The relief that she felt at the opportunity to tell her on story was a chance for her to connect and express her feelings about her loss. For both families (JM1 and JM5) telling their different stories had a sense of a therapeutic release, despite the inherent differences in the stories, one being of experiencing poor health and the other of bereavement. This is what Illouz [1] refer to as the "therapeutic narrative of selfhood".

This concept links well with the argument from MacAdams, 1993 cited by Bamberg which states that "the stories we tell are because they reflect the stories we are". This is evident in the way participants believe that only by being part of the research, it was their way of judging whether someone out there cared and or was listening to their plight. This was very apparent in the way that participant JM6 and her brother felt isolation caused by the pandemic and isolation from society at large had brought them closer together. They repeatedly use the phrases, 'very very lonely', and 'very very isolated' to describe their situation.

Riessman argues that a "Narrative analysis can forge connections between personal biography and social structure, the personal and the political". The research brought out strong emotive views from some community leaders about why their



communities would rather not participate in research that sought personal stories from their community members. It would appear that in some communities, issues are viewed on the basis of “we” versus “them” perspective [13].

On the subject of health inequalities, it is quite staggering that the majority of stories mention an aspect of social inequality that consequently brings to the fore, issues of health inequalities as a social reality in the community. There is no surprise in this since the 2021 report by The Health Foundation on the COVID-19 Pandemic which is 78 pages long, explains in detail the way health inequalities were exposed by the pandemic) [9].

The issues of housing and provision of good healthcare cannot be separated from the other issues discussed above as demonstrated in the story of JM6, where two adults (a brother and sister) shared the same bedroom in a multi-occupancy house, with the sister sleeping on the floor and the brother on the bed, whilst the brother has stage four cancers. The issues of social inequalities are inextricably entangled with health inequalities and the associated effect of experiencing poor health (ibid). This explains why the Faith Leaders refused to view this CoCo service review as a distinct and separate initiative from everything else happening around them, something that is quite understandable. One of the issues raised by one of the religious Faith Leaders was that “we will not recommend anyone from our community to participate in any research until the issues identified by previous research have been implemented”. They gave me this impression that Ethnic Minority groups feel ‘over researched’ and maybe ‘used’ by researchers.

The issue of social isolation is a big issue for this family (JM5) as the sister needs to work “so as to earn a living” and that leaves the brother isolated and desperate for company. Both of them could not wait for Compassionate Communities volunteers to start coming and be a befriender.

At another level, the issue of health ‘as a moral practice’ [14] was evident across the board in the narratives that are being analysed here in terms of the intrinsic evaluation that patients and their relatives give about the services they receive from the hospital at large and from the Chaplaincy department in particular. Their frame of reference questions whether the provision of a service is moral and just regardless of the fact that they have a faith or not. A case in point is that of JM1 and the treatment of the body of her dad after he passed away by a named funeral Director resulting in their taking their dad’s body to different funeral directors. She was hurt by the way that his body was ‘manhandled’. This is a clear example on how moral standards on matters such as respecting the handling the body of deceased person with dignity means to different people [15].

The lack of support or perceived lack of support or empathy for JM2 when her mother passed away was an affront to her notion of morality for someone grieving [16]. From JM2’s point of view, she felt that the hospital staff where her mum passed away should have been aware of her and her family’s needs on moral grounds and how she feared being judged according to stereo types about her race as an Indian woman [17]. She asserts: “With Indian families we express our grief, we cry, we express our grief and sometimes the comments you get from people that don’t understand is, ‘oh, yeah [18]. These Indians

are always crying, there’s too many of them, they are all you know...” This sums up the different views people have towards death and bereavement and the fact that some communities feel less valued, and their practices derided shows the tension between people in the same community from different backgrounds and creates an atmosphere of suspicion anchored in the ‘we and them’ paradigm [19]. It is therefore important to note that health as a moral practise is not a place of convergence, but rather a field of contestation. This is a lesson that healthcare care givers in differentiated settings can learn from [13].

## CONCLUSION

One of the clear lessons to come out of this Service Review was that most of the participants and people we contacted in the process of doing this research were unaware of the existence of Compassionate Communities services. Our approach to publicising the CoCo service has been to display banners about the service around the hospital and other community venues where we hold our activities such as at RIPPLE and TAB and also at Bereavement Point venues across the hospital’s catchment areas. We have had to send NHS Trust wide emails and distribute fliers and circulate them among people in our networks as the movers of Compassionate Communities. The only participant that acknowledged that they had seen one of our CoCo fliers was at the GP surgery and her conclusion was that it was not meant for her. Here is what she said: If there were posters in the places that I would sort of go to. If that poster, that leaflet had been up at the Gurdwara, I would have known that it is here for a reason. Without the research we would never have known that where you post a flier has a huge significance in terms of its acceptability. Our use of banners and posters meant that we have only been able to reach a limited number of people within these circles (mentioned above), but the main problem is that we only used the traditional methods for sending out information about hospital programmes. As a result we have become victims or slaves of tradition rather than be innovative about mediums and media that are most relevant for what we want to achieve. JM10 for example was advocating the use of Social Media to promote groups of people suffering from the same condition, something that deserves further investigation.

One of the participants JM2 had a partial answer to how to get information into the community especially into the Ethnic Minority Community. In her experience of working with Asian women in her previous role, translating fliers into community languages, such as Bengali, Urdu, Punjabi, Somali, did not achieve the desired result as the majority of the women that spoke these community languages could not read even those translated fliers. She later discovered that the best way to disseminate information to in her community was through, Community Radio stations, something that needs further exploration.

On another note, a link with other healthcare providers and professional could strongly enhance the awareness of CoCo in the community as JM9 says “... the professionals the GP or the carers or the social workers, they should be saying you know, if you need this as a service, there is this (CoCo) out there.” One of the Faith Leaders was also suggesting that the hospital

departments that treat the kind of patients that we were targeting could have helped in identifying participants from their clinic groups. There is therefore need for greater cooperation and awareness of CoCo within the Trust.

The other problem highlighted by one of the faith leaders in focus group discussions is that programmes intended for ethnic minority communities tended to take a “one size fits all” without due consideration to differences within communities. Such a blanket approach does not always work as different communities have their own idiosyncrasies.

As the chaplaincy department the idea of carrying out research in the Ethnic Minority Community good and noble, as ‘we wanted to know why things where the way they were’. It was quite a revelation to learn that research was a ‘sore subject’ in that community. According to the Faith Leaders, all what researchers needed to know about the community was already known. The community they represented was tired of being researched without the implementation of the results from the previous researches.

What we offer as Compassionate Communities in terms of care for the dying, befriending services, bereavement support, to the ethnic minority community ‘that has a faith’ it seemed contestable, for a number of reasons. Some of these communities argued that they have established extended family and faith networks that support people experiencing loneliness in time of distress, to varying degrees of sufficiency. Faith Leaders said that they had “safe neighbourhood committees” that took care of some these needs. The issue or concept of safe neighbourhoods was however heavily contested by the females from the same community in the focus group who argued that these committees were either non-existent or inadequate or gender biased.

Linked to the notion of gender bias, ladies in the focus group argued that it is difficult for an ‘Asian woman’ to talk about how they are suffering in general and especially for Moslem women, since they have this religious concept in Islam called ‘doing Saba’. ‘Doing saba’ means if you are experiencing problems, you do not complain or talk about it as you risk not getting the blessing that comes with the trial. It is similar to the Christian concept of ‘carrying one’s cross and following Christ daily’ JM8 sums it nicely when she says: I think in my community, we are all very strong women, and in my family, my relatives are all taught to get on with it. The issues of ‘shame’ and ‘honour’ were huge topics and women would be very careful about what they say to a data collector about their personal story, whether the data collector was known to them or not, as one would be very careful not to say something that brings dishonour and shame to the family, this concept is found in a number of faiths and cultures in the ethnic minority community.

The lessons learnt were invaluable and these lessons are not only for the Chaplaincy Department and Compassionate Communities but also for many different departments across the Trust, ranging from Quality, to Palliative Care. There is a rich vein wealth in terms knowledge, insights and wisdom that we can learn from each other if we just stop and listen to the story that each one has. The narratives collected in this research are a testament of the riches that we collectively have as a community.

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## CONFLICT OF INTEREST

None

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