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What Does Compassion Mean to the Black Community of San Diego?

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What Does Compassion Mean to the Black Community of San Diego?

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Abstract

Due to many historical injustices, communities of color have often felt misused by medicine at large. There is a cycle of distrust and general unpleasantness with healthcare providers. Unfortunately, the injustices haven't stopped, as many people of color feel that those in the medical profession lack one of the basic qualities that are needed in healthcare: compassion. In many research studies about compassion, healthcare professionals and other experts define compassion. However, the people we should be asking are not the providers themselves, but the patients, as they are the ones that will know if they receive compassionate care. Focusing research like this on communities of color, especially since there is already distrust, is important. Although research on compassion has increased, there is little data on how under-resourced, culturally, and ethnically diverse communities define compassion, which can help mitigate the health disparities plaguing these communities. This study will help delineate how compassionate the healthcare industry is, and if it is not, what work can be done to make it more compassionate. A purposely made survey was created with a focus group of Black community leaders, non-profit founders, and physicians from San Diego. This survey is composed of questions that target experiences and attitudes towards physicians and healthcare providers for people from the Black community to expand on. Therefore, the Black community, across all socioeconomic groups, can be directly asked what compassion personally means to them, allowing us to finally understand 'What Does Compassion Mean to the Black Community of San Diego?'

Introduction

Compassion is the standard of care and the foundation of medical practice. It has been shown that compassion in a patient and provider relationship is beneficial, as it improves patient satisfaction (Nápoles et al., 2009), leads to faster recovery for patients (Sinclair, Norris et al., 2016), and helps with the discussion of sensitive health-related topics between patient and doctor (Lori et al., 2010). Although compassion is important in improving healthcare, there has been little research done on it from the perspective of the patients and their expectations of their healthcare providers (Sinclair, Norris et al., 2016). Instead, the definition of compassion as related to the healthcare profession has been defined more by the words empathy and sympathy, or the term will be used without any clear definition (Singh et al., 2018).

As research on compassion increases, a difference has been seen through the ways that the providers and patients perceive compassion (Sinclair, Mcclement et al., 2016), especially how underserved, culturally diverse, minority populations define compassion (Singh et al., 2018). This leads to the continued distrust between these populations and the healthcare industry, specifically with African-American communities. With the knowledge of many past historical and personal experiences with healthcare, many African-Americans feel a sense of mistrust and distance between themselves and their healthcare providers (Kennedy et al., 2007). To understand and shape the way compassion is received and valued by patients, especially those in diverse communities, a certain metric or toolkit on compassion must be created that addresses and enforces compassionate care in the way these communities define it.

There has been a recent effort to further the understanding of compassion in diverse populations. A research study conducted by palliative care specialists in Calgary, Canada led to the first patient-derived, clinically applicable model for understanding compassion in 2018. Named the Patient Compassion Model (PCM), this tool was developed by collecting qualitative interview data from patients within a palliative care unit, and then the grounded theory approach was utilized to identify recurring themes. Though this research is limited by the advanced cancer patient population in the palliative care unit, the model was later successfully generalized and transferred to other palliative patient populations. The research findings suggest that the PCM may be generalized and transferable to other unstudied patient populations and may even be used to inform education and research (Sinclair, Jaggi et al., 2018).

Although debate exists on the teachability of compassion (Bray et al., 2013), there is evidence to support that the development of compassion can be taught in medical education settings, as seen through the Jefferson Scale of Empathy (JSE). The JSE was developed in order to measure the empathy of health professionals. This 20 question assessment tool relies on 'Compassionate Care' as one of its three measures of empathy, however here compassion is defined as 'sympathy combined with the desire to help,' a definition determined by foundational surveys administered to physicians and not patients (Hojat et al., 2001). A 2008 pharmacy school study showed that pharmacy students who underwent structured patient empathy training had improved JSE scores after training, however, statistical significance was not determined due to the small sample size (Chen et al., 2008). Although these two past studies and testing metrics were created and used, there continues to be a lack of research on compassion-related health professional curriculum interventions in general, let alone in underserved and diverse communities.

It is important that continued research efforts to understand compassion from the perspective of diverse, underserved communities is done through the lens of cultural humility. 'Cultural humility,' as opposed to cultural competency, is a non-paternalistic and mutually beneficial approach to readdressing power imbalances in the patient-physician relationship by ensuring that health care providers commit to life-long learning and persistent self-critique. This outlook is especially relevant for cross-cultural care relationships. As importantly inferred by the researchers who defined cultural humility, "Experiencing with the community the factors at play in defining health priorities, research activities, and community-informed advocacy activities requires that the physician trainee recognize that foci of expertise with regard to health can indeed reside outside of the academic medical center and even outside of the practice of Western medicine" (Tervalon et al., 1998) Between the months of June and August of 2021, time was dedicated to determine what compassion means to the average black individual in San Diego and what providers can do to ensure that compassion is given to their patients.

Methods

After obtaining approval for the study from the Institutional Review Board, a focus group composed of Black community leaders, non-profit leaders, and physicians was created to ensure that the entire study process was welcoming and not offensive to Black individuals at large. This required having conversations on where the medical community has gone wrong towards the Black community and expectations of the outcome of this study. After gathering sufficient information and guidance from the focus group, a survey to determine what compassion means to this community, The Compassion Survey, was made using Qualtrics. The survey contained 33 questions to gather insight about the participants' experiences with medicine and understanding what compassion means to them, including characteristics of compassionate people and feelings on the culture of medicine and how it relates to Black individuals. Once finalized, the survey was distributed to relevant participants through in-person and virtual administration. For the in-person administration, participants were chosen from various outdoor events in San Diego, such as the monthly Community Health & Resource Fair at the Jackie Robinson YMCA. Once the survey was completed, participants were given a $10 Amazon gift card and the option to enter in a gift basket raffle as a token of gratitude and compensation for their time.

Results

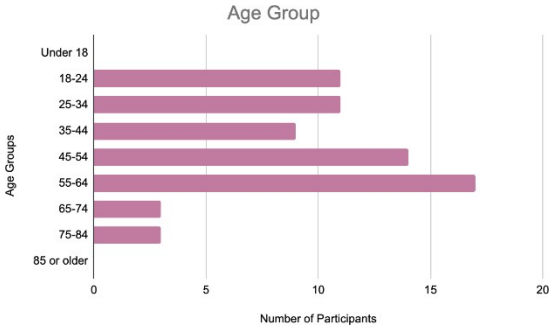

Figure 1: Breakdown of Participants by Age Group

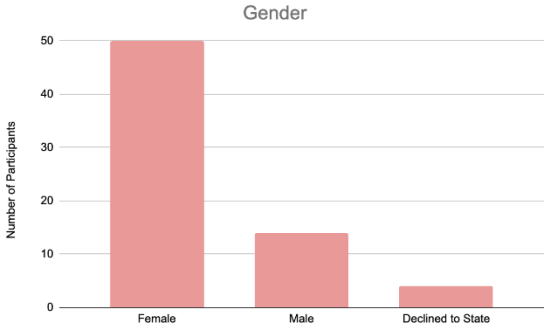

Figure 2: Breakdown of Participants by Gender

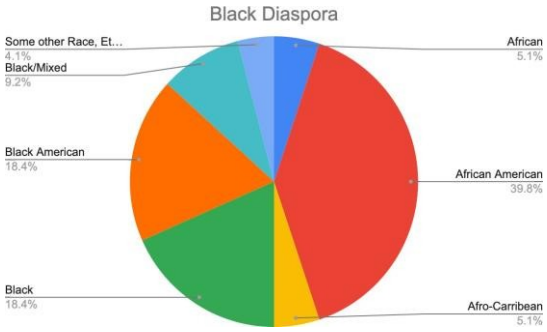

Figure 3: Participants self-identification within the Black Diaspora

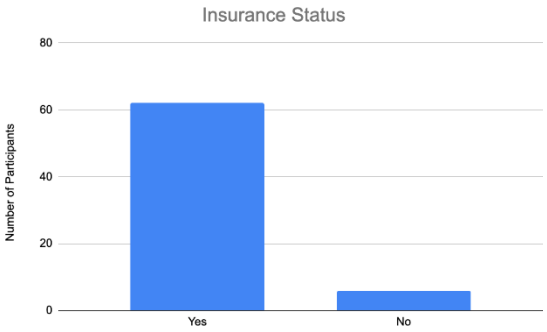

Figure 4: Participant Insurance Status

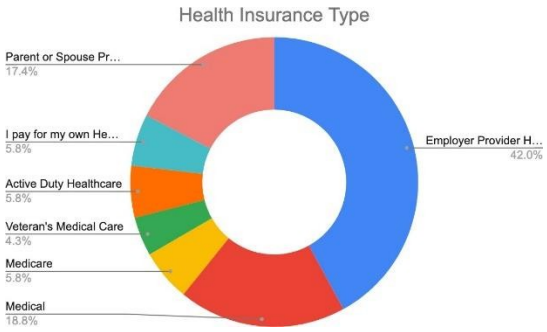

Figure 5: Breakdown of Participants by Type of Healthcare Insurance

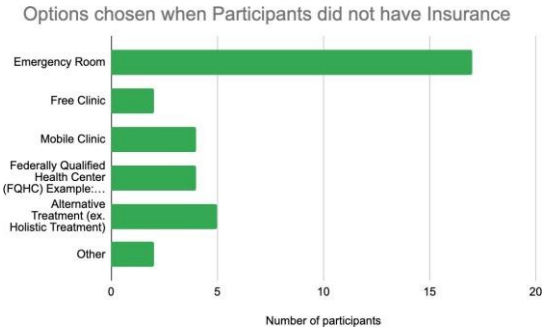

Figure 6: Chosen healthcare options when participants did not have insurance

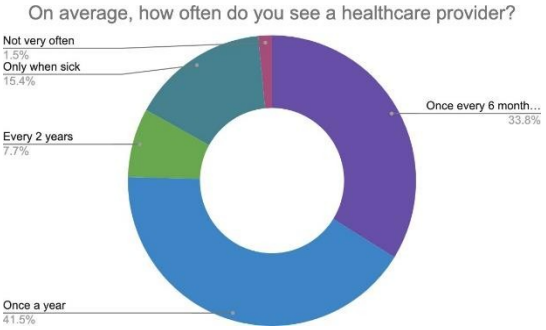

Figure 7: How often survey participants saw their healthcare providers

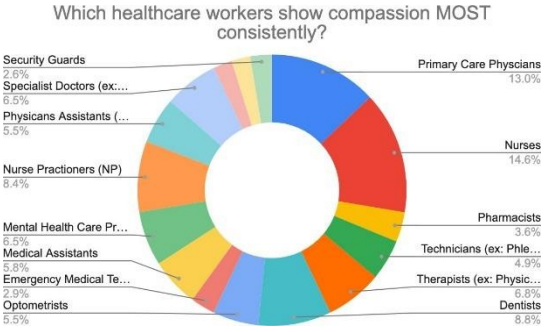

Figure 8: Healthcare workers that show the most consistent compassion towards survey participants

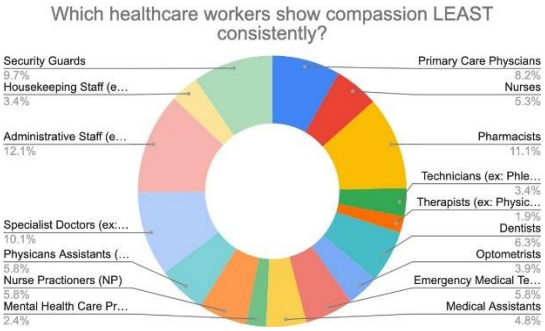

Figure 9: Healthcare workers that show the least consistent compassion towards survey participants

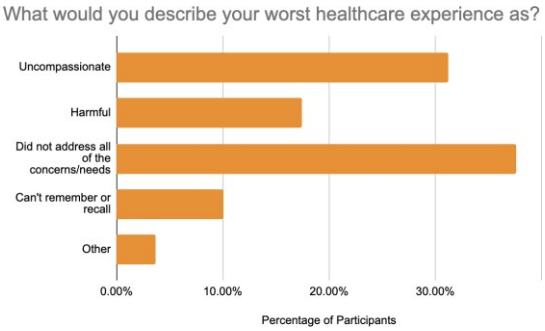

Figure 10: Survey participant descriptions of worst healthcare experience

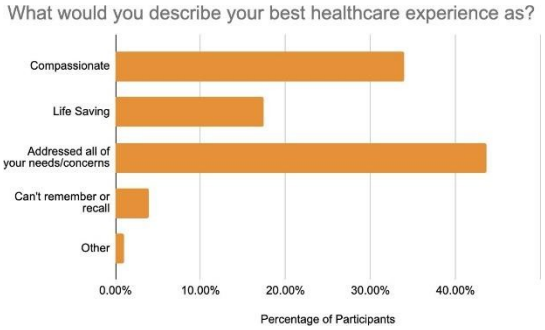

Figure 11: Survey participant descriptions of best healthcare experience

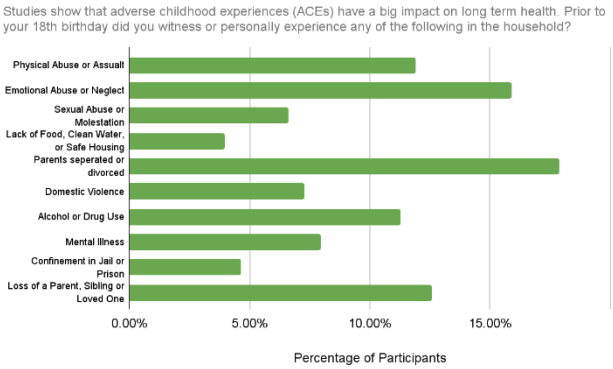

Figure 12: Percentage of survey participants that suffered varying adverse childhood experiences prior to their 18th birthday

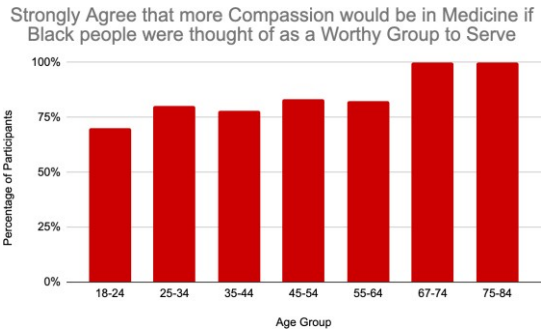

Figure 13: Age breakdown of survey participants that strongly agree that there would be more compassion in medicine if Black patients were thought of as a worthy group to serve

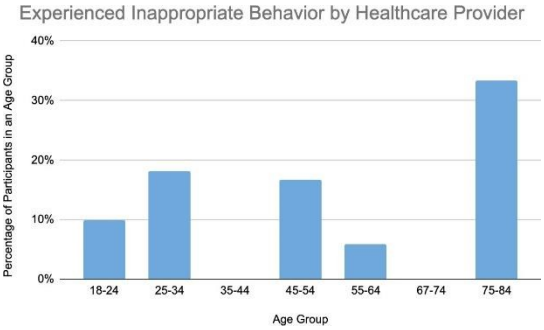

Figure 14: Age breakdown of survey participants that experienced inappropriate behavior by a healthcare provider (ex. Inappropriate suggesting or touching)

Trust their healthcare provider	76.6%
Receive routine physical exams	75.41%
Percentage of the time that participants were treated fairly by their providers	63.1%
Experienced inappropriate behavior by healthcare providers	11.1%
Providers never or rarely took the time to get to know or understand the barriers facing a community	64.7%
Believe that compassion is lacking due to providers not believing that they are a worthy group to serve	81.0%

Table 1: Summary of Responses about Healthcare

Percentage that expect compassion from healthcare providers	98.41%
Percentage of participants that had health providers show compassion to get know participants' adverse experiences	76.41%
Strongly believe that there would be more compassion if there were providers that looked like them	66.2%
Strongly believe that to be considered compassionate, providers must acknowledge and understand the professional and systemic racism in medicine	64.1%
Strongly/Somewhat/Neutral agreement that compassion can be learned in an academic setting	81.3%
Somewhat/strongly believe that compassion can be learned through life experience	92.3%

Table 2: Summary of Responses about Compassion

Kindness	100%
Empathy	100%
Willingness to Help	89.7%
Warmth	86.8%
Sympathy	64.7%
Resolve	55.9%
Wisdom	52.9%
Perseverance	48.5%
Pity	16.2%

Table 3: Characteristics of Compassion: Percentage of Participants Answering 'Yes'

	Always	Sometimes	Never
Makes direct eye contact	61.90%	38.10%	0.00%
Shows understanding of my culture	24.62%	56.92%	18.46%
Shows respect for my culture	39.06%	48.44%	12.50%
(Pre-COVID) Offers handshake	47.69%	30.77%	21.54%
Empowers me with knowledge	67.69%	24.62%	7.69%
Withholds knowledge about my health from me	6.15%	26.15%	67.69%
Listens to me	63.08%	35.38%	1.54%
Confirms what I said correct	43.75%	46.88%	9.38%
Gives me their undivided attention	69.23%	27.69%	3.08%
Refers to me with formal titles (Ex: Mr., Mrs., Ms., etc.)	43.08%	38.46%	18.46%
Offers alternative care (Ex: Holistic medicine, meditation, acupuncture, etc.)	27.69%	27.69%	44.62%
Makes conversation or small talk	43.08%	52.31%	4.62%
Shows interest in my personal life	23.08%	53.85%	23.08%
Shares information about their personal life	12.31%	44.62%	43.08%
Addresses all of my questions and concerns	56.25%	40.63%	3.13%
Rushes me	18.75%	31.25%	50.00%
Remembers me at the next visit	56.25%	39.06%	4.69%
Presents all my health care options	43.75%	42.19%	14.06%
Demonstrates warm-heartedness	45.31%	46.88%	7.81%
Shows trustworthiness	54.69%	43.75%	1.56%
Shows common courtesy	68.75%	31.25%	0.00%
Demonstrates open-mindedness (receptive to new people or new ideas)	32.81%	59.38%	7.81%
Makes assumptions about me	12.70%	47.62%	39.68%
Recognizes that I am the most knowledgeable about my body	34.92%	44.44%	20.63%

Table 4: Summary on provider mannerisms when meeting patients

Discussion

During the administration of The Compassion Survey between the months of June and August, a total of 68 participants took part in the survey process. Up until July 12th, 2021, the online software Docusign or verbal consent was used to have participants read the informed consent document and enter the gift basket raffle until the informed consent document was incorporated into the Compassion Survey. Additionally, only participants who were above the age of 18 and who self-identified as part of the black community or part of the Black Diaspora were allowed to complete the survey. Figures 1-7 provide a demographic insight into the survey participants, identifying the breakdown of the group's age, gender, self-identification within the Black Diaspora, insurance status, chosen healthcare options if participants didn't have insurance, and how often participants saw their healthcare providers.

Participants indicated that nurses are the group of healthcare providers that show the most consistent compassion (Figure 8), while pharmacists showed the least consistent compassion (Figure 9).

From Tables 1 and 2, it is apparent that many black individuals believe that compassion is lacking due to providers never taking the time to understand the barriers facing their community or even creating an environment for their patients to feel that they are individuals who are worthy to serve. Many in opposition to the enforcement of compassionate care curriculum in healthcare learning institutions say that communities of color were victims of racism before but with antiracist education and rhetoric becoming more prevalent in all aspects of life, it should no longer be apparent in current times. However, this is far from true. As seen in Figures 13 and 14, participants across all age groups - even those that are 18 years old - have experienced inappropriate behavior and inadequate levels of worthiness at one time from their providers. This is even more disheartening when at many times, these participants probably needed the compassion and care from their providers as they experienced things like physical abuse, sexual abuse, domestic violence and other adverse childhood experiences before the age of 18, as shown in Figure 12.

This is most likely due to the fact that the medical community has not done the work to fully address and make changes to the racist environment in medicine. Survey participants indicated that providers would be more compassionate if they addressed and understood the professional and systemic racism in medicine (Table 2). In some medical schools, there is only "one lecture during medical school on health disparities, and just one unsurprisingly uncomfortable reflective practice session on the topic of racism" (Tervalon et al., 1998). As seen by data from the Compassion Survey, that kind of education is not enough to change the culture of medicine, as it does not help providers be as compassionate and understanding as they need to. However, instead, the curriculum should be more in-depth to educate providers about structural racism and implicit bias while promoting antiracist behaviors. From the data, it can be seen that many patients view a successful healthcare experience as one that is able to address all their concerns and needs while also showing compassionate mannerisms (Figures 10 and 11). It should also incorporate additional characteristics of compassion such as 'kindness', 'empathy', 'willingness to help' and 'warmth' while making sure to shy away from the act of pitying black patients as that is not viewed as a compassionate act (Table 3), which can be embodied by the positive

mannerisms that are identified in Table 4. This, in combination with the continued advocacy of compassionate care, will hopefully lead to rebuilding the trust between the healthcare system and communities of color.

While continued advocacy is necessary, compassion curriculum in medical education should be added as well. Although compassion is an important quality for admissions to medical school (Sinclair, Hack et al., 2018), medical students could potentially lose some of the compassionate traits and tendencies throughout the four rigorous years of medical school and the years of residency and fellowship after. Since survey participants believe that compassion can be learned in an academic setting, the most comprehensive compassion curriculum would also include education on the personal and systemic racism in medicine along with understanding the challenges or barriers that burden communities of color. An ideal curriculum would also include a way to measure the increase in compassion levels throughout the whole process, which might possibly be used in conjunction with the Jefferson Scale of Empathy. Once the acknowledgment and work are done to make healthcare workers more compassionate, especially with communities of color, it can be a step in the right direction to give patients the best experience with their providers as they can.

Future Research

In the future, a longer period of time will be needed to perform additional data collection, especially for other communities of color and possibly to other areas of California. Most of the data collection was done between the months of June-August 2021 and the survey was solely administered in San Diego. However, to gather more input from different communities about what compassion means to them the survey will need to be extended to different regions and communities to allow for a more comprehensive understanding of compassion. Additionally, since there was a small number of participants, there was not enough data to perform meaningful, detailed statistical analysis to determine the significance of varying factors that were studied.

Conclusion

While there is still work to be done to fully understand what compassion means to the black community and other communities of color, we have at least have a better understanding of what it means and how providers can take the steps to ensure that their patients have compassionate experiences. With interspersed compassion trainings throughout the time these providers are receiving their respective health career training, that highlight the importance of understanding personal and systemic racism that is in medicine, we can be sure that patients and their experiences continue to remain at the forefront of these providers' minds, hopefully leading to the rebuilding of trust between medicine and communities of colors.

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