GHANA INSTITUTE OF JOURNALISM (GIJ)

SOLUTIONS JOURNALISM AS A DEVELOPMENTAL TOOL IN INCREASING RARE DISEASES AWARENESS IN GHANA

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STUDENT'S DECLARATION

I hereby declare that this dissertation, with the exception of quotations and references contained in published works which have all been identified and duly acknowledged is entirely my own original work, and it has not been submitted, either in part or whole, for another degree elsewhere.

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Esmeralda Arvo-Quardoo

10th December, 2021

Date

SUPERVISOR'S DECLARATION

I, hereby declare that the preparation and presentation of this work was supervised in accordance with the guidelines for supervision of dissertation as laid down by the Ghana Institute of Journalism, Accra.

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DEDICATION

I dedicate this work in memory of my adorable Son who exposed me to the knowledge of rare diseases. This original work is also dedicated to all Spinal Muscular Atrophy patients and the 300 million persons living with a rare disease across the globe as well as researchers who are working round the clock to secure treatments for the over 95% of the 7000 conditions who currently do not have a cure.

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ABSTRACT

Rare diseases more and more are becoming prevalent in the Ghanaian society with little to no attention paid it by healthcare practitioners, researchers and policy makers. The purpose of this research was to examine the knowledge of rare diseases among a cross section of the public, clinicians and the media to better understand other studies within the Ghanaian context. Using thematic analysis, the study analyzed the data on rare diseases among clinicians and the public. Again, the SPSS version 16 was used to analyze the coverage of rare diseases in the dailies to establish the prominence given rare disease stories. The study established a fair awareness of clinicians and the public on the subject of rare disease. However, the issue of diagnosis above everything and throughout the study proved to be an important step in dealing with the gaps identified within the rare disease ecosystem in Ghana. Further studies are required to increase awareness using the media as a tool and to draw researchers as well as policy makers' attention to addressing the issues of rare disease.

CHAPTER ONE

1.0 Introduction

It has been observed that journalism has immensely contributed to society's development through time, albeit at a pace relative to specific society's need and goal. Although journalism has contributed in fostering development in certain societies, it has similarly weakened others. For instance, while the medium of media are used in some countries to disseminate information on the latest technological solutions and advancement, others use it to magnify the woes of their societies thereby dampening their morale and contributing to what Kinnick, Krugman & Camercon call "compassion fatigue" (Kinnick, Krugman, & Camercon, 1996). Mostly, in an attempt to hold an accurate mirror to society, media tend to make problems scream while solutions whisper- a pattern that has stalled the development of many societies. In view of this, solutions journalism- a novel strand of journalism with the aim of proffering solutions to identified challenges within a society- has been developed to provide a platform to share solution based stories aimed at heightening connection between audience and news organizations in addressing societal problems while reducing compassion fatigue (Curry & Hammonds, 2014).

As a developmental tool for this study, solutions journalisms' concept would be adopted in providing a module for improving rare disease awareness and knowledge in Ghana. To achieve this, the study would examine rare disease coverage in the Ghanaian media using the guideline, recommend a better coverage of rare disease stories that will not only show despair but processes employed in seeking solutions for the rare disease community in Ghana. It is an appropriate developmental tool because solutions journalism concentrates on working towards a solution and focuses not only on what may be working, but how and why it appears to be working, or, alternatively, why it may be stumbling (Curry & Hammonds, 2014).

1.1 Background of the Study

1.1.1 Rare Disease Definitions

Rare diseases are diseases that are caused by changes in genes or chromosomes which cannot be altered resulting in the lack of a cure for 95% of the over 7000 rare diseases identified globally (GARD, 2021). Most rare disease definitions are prevalence based and due to the lack of epidemiological data, deducing the population threshold that defines rare diseases is difficult (Cui & Han, 2017). The World Health Organization (WHO) defines rare diseases as often debilitating, lifelong disease or disorder with a prevalence of 1 or less, per a 1000 population (Ministry of Health and Family Welfare, 2021). Japan describes a disease as rare when its etiology is unknown, lacks effective treatment, presents a major financial and psychological burden and affects fewer than 50,000 patients (Song, Gao, Inagaki, Kokudo, & Tang, 2012). The European Union deems a disease as rare when it affects 1 in 2000 people (European Commission, 2011). America recognizes a disease as rare when it affects fewer than 200,000 people (GARD, 2021). In furtherance, a disease is considered rare in China, when it affects 1 in 500,000 people, (Cui & Han, 2017) and India perceives a disease as rare when it affects 1 in 2,500 individuals (Rastogi, 2021). Sadly, there is no official definition for rare diseases in South Africa and by extension Africa, hence most stakeholders fall on the European Union definition of rare disease (Conradie, Malherbe, Hendriksz, Dercksen, & Vorster, 2021).

1.1.2 Rare Disease Statistics

Rare diseases affects one third of the world's population, accounting for 263-446 million people (3.5-5.9 percent) being affected by one disease or the other (Wakap, et al., 2019). Although prevalent globally due to the various types, the awareness and rarity of a disease varies from country to country and from continent to continent as a result of the paucity of knowledge of it by

healthcare practitioners and families, a lack of data on its occurrence and a lack of data sharing culture among countries (Shafie, et al., 2020; Li, et al., 2021). Sickle cell, autism, hepatitis and epilepsy for instance although rare diseases, are not considered rare in Ghana due to its high prevalence but may be considered rare in other jurisdictions. China has a rare disease population of 16.8 million, America 25-30 million, and the European Union 30 million. Africa's statistic remains unclear.

1.1.3 Rare Disease Facts and Features

Rare diseases mostly affects children and reduces life expectancy. Fact is, 71.9% of rare diseases have genetic causes with 69.9% occurring solely with pediatric onset. 50% of rare disease cases identified affects children below the age of five. 95% of rare diseases do not have Food and Drug Administration (FDA) approved treatment and it take about 7 years to properly diagnose certain types of rare disease (Project 8 P, 2021; Rare Genomics Institute, 2021). Rare diseases like Spinal Muscular Atrophy (SMA), Amyotrophic Lateral Sclerosis (ALS), Cystic Fibrosis, Duchenne Muscular Dystrophy (DMD) among others have a more harmful effect on health-related quality of life than other serious illnesses (Shafie, et al., 2020) - usually before a child's first year of life.

Rare diseases are characterized by disability, degenerative and progressive loss of motor neurons, vulnerability, are genetic and chronic in nature, life-threatening, and causes respiratory and hearing impairments (National Institute of Health, 2019). Much as these challenges exists within the rare disease ecosystem globally, efforts have been channeled to addressing the challenges with which rare disease persons live with. The committee for non-governmental organization and rare disease international (RDI) are working assiduously through collaborations with rare disease advocacy groups to improve the quality of life for persons living with a rare disease globally.

1.1.4 Rare Diseases - Europe's Paradigm

According to the European Union, a disease is considered rare when it affects fewer than 5 in 10,000 people (European Commission, n.d.). Universally, rare disease patients account for between 3.5-5.9 percent of the world's population equating to 263-446 million people. This translates into four percent of the world's population (Wakap, et al., 2019).

There are 7000 types of rare diseases with 70% starting in childhood and 72% percent having genetic causes (Wakap, et al., 2019). It is an established fact that only 5% of rare diseases have a cure, widely because the cost of developing and bringing to the market a medicinal product to diagnose, prevent or treat the condition would not be recovered by the expected sales of the medicinal product hence the unwillingness in developing the medicinal product under normal market conditions (EUR-Lex, 2000).

Rare disease patients in Europe do have access to quality health care systems that support diagnosis of rare disease through newborn screening. Newborn screening in European countries mandatorily check for over 25 rare conditions that could affect the child early in life (raisingchildren.net.au, 2021). Statistics show that early diagnosis through newborn screening has contributed to ensuring that about 12,500 babies with serious but treatable conditions grew up healthy (Baby's First Test, 2020).

Europe's rare disease policy for example has as its overall aim, a strategic objective to improve patient access to diagnosis, information and care. To do this, they hope to i) improve recognition and visibility of rare diseases- which they are working on through the UN Resolution4Rare Campaign as well as the Rare 2030 project. ii) Ensure that rare diseases are adequately coded and traceable in all health information systems. iii) Support national plans for rare diseases in European Union countries and lastly iv) create European reference networks linking centers of expertise and

professionals in different countries to share knowledge and identify alternative treatment options (European Commission, 2011)

As a global health issues, European countries have put structures and policies in place as well as advocacy groups to ensure that rare diseases along with persons living with them receive the needed attention, and orphan drug formulating processes initiated into the treatment of rare diseases. Advocacy groups such as Rare Action Network, Cure SMA, and regulatory bodies like the NGO Committee for Rare Diseases, Rare Disease Europe (EURORDIS) and Rare Disease International (RDI) are all working in synergy towards ensuring a better quality of life for persons living with a rare disease in Europe and around the world.

1.1.5 Africa's Rare Diseases Eco-System

Conversely, Africa's rare disease ecosystem is an understudied population with specific challenges (Baynam, et al., 2019). With a paucity of research into the rare disease field, a lack of registry, lack of clinical expert in the field of rare diseases, a lack of awareness of rare disease among clinicians and families, the association of rare diseases to curses or punishment from the gods, lack of access to diagnostic services, lack of newborn screening, a lack of policy, lack of vocal community support groups, lack of a data sharing culture and high cost of treatment for rare diseases-the issues of rare disease management in Africa provides an opportunity to collaborate and tackle the problems while improving the quality of life for persons living with rare diseases in Africa (Baynam, et al., 2019).

To address these challenges that the African rare disease community face however, jurisdictional initiatives must be coordinated with international research, development and collaboration across health systems to ensure that the outcomes of these activities accrue to the benefit of patients and families in Africa and around the world. (Schieppati, Henter, Daina, & Aperia, 2008).

The international rare disease research consortium (IRDiRC) has initiated steps into coordinating international research in ensuring that Africa's rare disease ecosystem receives the needed support it require to tackle the dynamism of its rare disease problems. To do this, it has connected private and public sponsors of research, patient advocacy groups and scientific researchers to i) coordinate diagnoses for patients suspected with a rare disease within a year of detection; ii) channeled undiagnosed individuals into a global pipeline known as the undiagnosed disease network international for further action; iii) aims to have 1000 new therapies for rare diseases approved by 2027; and ultimately iv) encourage newborn screening as an essential part of rare disease diagnostics (Baynam, et al., 2019).

The above listed processes are imperative since diseases with low prevalence are usually not of precedence for national health program. Innovative approaches such as healthcare provider trainings, awareness campaigns to improve knowledge of rare diseases, deliberate research into rare disease, newborn screening programs, rare disease policy among others would thus be required to make Africa's rare disease ecosystem a better one while improving on the quality of life of rare disease patients.

1.1.6 Rare Disease Treatments

Rare diseases are treated by a group of medications known as orphan drugs. Due to the rarity of these diseases, they are "neglected" by the pharmaceutical industry because the market is usually seen as unprofitable (European Organization for Rare Diseases, 2005) since orphan drugs are usually expensive to develop and hence expensive to access. As a result, governments in advanced countries have supported scientist with the research and manufacturing of such drugs. Similarly, given that rare diseases represent a global public health problem due to the lack of appropriate treatments, multiple hospitalizations over a lifespan, and a lengthy diagnostic odyssey, the

National Institute of Health (NIH) continually invests in rare disease research and orphan drug manufacturing. In 2011 for instance, the NIH allocated about 3.5 billion dollars to rare disease research and 750 million dollars for orphan drug development activities (Groft, 2013)

Spinal muscular atrophy (SMA) -one of the rare diseases- is a severe neuromuscular disease characterized by the degeneration of alpha motor neurons in the spinal cord, resulting in progressive proximal muscle weakness and paralysis (D'Amico, Mercuri, Tiziano, & Bertini, 2011). Approximately 95% of all individuals with SMA have a homozygous deletion of the survival motor neuron 1 gene; a common path of relatively greater progression of weakness or departure from a normal pattern of developmental gain of milestones, followed subsequently by a slower plateau of relative stability with very slow worsening (Glascock, et al., 2018). SMA is one of the most common genetic causes of infant death (Moultrie, Kish-Doto, Peay, & Lewis, 2016). It is estimated that 4 in 10 people are unknown carries of the SMA gene.

This disorder comes in five types: type 0 referring to fetal onset with severe weakness, joint contractures, and respiratory compromise presenting at birth; Type 1 known as the Werdnig-Hoffman disease is characterized by weakness in the first six months of life, infant never achieve the ability to sit independently, it constitute sixty percent of all SMA cases; Type 2, known as Dubowitz disease or intermediate SMA, is recognized later in infancy, with the infant having the ability to sit but not walk independently constituting thirty percent; Type 3 (Kugelberg-Welander) constitute about ten percent of cases and is characterized by the ability to walk. The last and final group are the Type 4 who show weakness in adult years (Glascock, et al., 2018).

Treatments for SMA are known to be very expensive. There are three types of treatments for SMA. The first treatment that received America’s Food and Drugs Administration approval in 2016 was Spinraza (Nusinersen) and it costs about $750,000 for the first dose and $375,000 subsequently

for the rest of the patient's life (Managed Health Executive, 2020). Zolgensma, a one off gene therapy treatment and the second type of treatment was approved in 2019 and costs £1.79 million per dose with an efficacy lasting more than five years after treatment. Zolgensma is also known as the world's most expensive drug (Weston, 2021). The third and recently approved treatment in 2020 called Evrysdi (Risdiplam) is the first oral suspension that can be administered at home and is priced around $340,000 for an 80 milliliter bottle (Genentech, 2020; Managed Health Executive, 2020).

Capturing patients view on treatments, a survey conducted in Europe revealed that persons living with a rare disease although do not expect to be cured from their disease hope to have an improved quality of life and as a priority, have access to treatment, better care coordination and multidisciplinary healthcare; integrated social care as well as a call into research that benefits every rare diseases (Dubief, Kole, Berjonneau, & Courbier, 2021) since the treatment for rare diseases put financial strains on persons living with a rare disease, running them bankrupt and reducing their quality of life. The call for efforts in every regard, therefore must be heeded to by the powers that be to reduce the burden on families as scientist work round the clock to increase treatment for rare disease patients in Europe and by extension across the world.

1.1.7 Ghana's Rare Disease Landscape

Rare disease in Ghana although rare are not so rare after all. Of the 7000 types of rare diseases identified globally, Ghana is said to have recorded 15 types and counting. Notable among them are spinal muscular atrophy, sickle cell disease, mucopolysaccharidosis, cerebral palsy, osteogenesis imperfecta, progeria, treacher-collins, down syndrome, thalassemia, anorectal malformation just to mention few (Rare Disease Ghana Initiative, 2021).

People living with rare diseases in Ghana however, face a myriad of issues, some of which include clinicians' lack of knowledge of most of the rare diseases which causes a diagnostic odyssey, the lack of a rare disease registry, the lack of Food and Drugs Authority (FDA) approved drugs- although the authority published a guideline for registering orphan drugs in 2019, the lack of access to diagnosis and diagnostic facilities as a result of under resourced laboratories, lack of access to treatment, high cost of treatment and the lack of financial wits to undertake diagnosis, limited media engagement and advocacy for rare disease, a lack of a rare disease policy, just to mention a few.

Furthermore, due to the disabling nature of most rare disease conditions, person living with rare diseases are unable to adequately secure employment which in turn makes them a socially isolated and impoverished population facing stigmatization and discrimination.

1.1.8 Ghana's Health Policy

Ghana's health policy over the years have concentrated on decreasing under 5 mortality rates, malaria and non-communicable diseases. Not much attention has been paid to rare diseases and newborn screening. According to Ghana's Newborn Health Strategy and Action plan 2014-2018, the common causes of neonatal mortalities are prematurity, birth asphyxia, infection, low birth weight and adverse intrapartum events without any record of rare conditions that can be contributing factors. It is worthy of note that Africa possesses eleven percent of the world's newborn population with twenty five percent of newborn deaths occurring in 2013 alone; fifty percent of such deaths occurred within the first 24 hours of life and seventy five percent occurred by end of the first week.

To address this challenge, the every newborn action plan (ENAP) initiated during that period focused on i) providing optimal services for mothers and children as well as newborns; ii)

integrating and implementing superior reproductive, maternal, newborn and child health care; iii) addressing equity issues by reaching the poor and under-privileged groups through universal coverage of the high-impact interventions; iv) ensuring transparency, good oversight and accountability; and v) employing innovative methods such as newborn counting as a measure to track the program and get better results (Ministry of Health, 2014).

Again, the revised edition of the national health policy (2020) also failed to address with specificity the issues of rare diseases as it also concentrated on maternal mortality, infant mortality, and life expectancy with a focus on these five thematic areas: i. To strengthen the healthcare delivery system to be resilient; ii. To encourage the adoption of healthy lifestyles; iii. To improve the physical environment; iv. To improve the socio-economic status of the population; v. To ensure sustainable financing for health.

Much as the policy document acknowledges not fully reaching the desired level of health because it has not comprehensively addressed the key determinants of health, it tries to address certain shortfalls within the health sector. In speaking to the issue of non-communicable and genetic diseases under which rare diseases fall, the document made mention of sickle cell- the most common in the rare disease chain but was quick to acknowledge that services (preventive, promotive, curative, rehabilitative and palliative) are not appropriately designed to account for populations with unique needs such as persons with genetic disorders among others. Although some rare diseases are characterized by disability, the policy document cites three percent of the population having some form of disability neglecting the rare disease statistic while recognizing an increase in the prevalence of neuro-degenerative disorders. To address the key determinants of health while strengthening the healthcare delivery system, the policy intends to adopt a life course approach which will appropriately reflect the complex nature of Ghana's disease burden and

ensure the availability of equitable care for respective population cohorts (Ministry of Health, 2020).

Furthermore, as part of processes to advance healthcare for persons living with a rare disease, the Food and Drugs Authority in 2019 approved a guideline for the registration of orphan drugs (Food and Drugs Authority, 2019) - drugs that are used to manage rare diseases- since none of them are manufactured within the country. This approach signaled a ray of hope to the rare disease community in Ghana and provided pharmaceutical companies the green light to import them although at a supper expensive price. Rare diseases are not specifically captured in the revised health policy neither has it been included in the national health insurance scheme. Patients therefore would have to bear the cost of accessing these orphan drugs when made available within the country.

Overall, the policy document reiterates Ghana's commitment to achieving Universal Health Coverage (UHC) while explaining what Universal Health Coverage means to Ghana that is timely access to high quality health services irrespective of one's ability to pay at the point of use (Ministry of Health, 2020).

1.1.9 Media Coverage of Disease

Media, known as the fourth realm of the estate has over the years had the responsibility of mirroring and shaping societies to ensure they reflect the dynamics of the societies in which they operate and by extension the global village they mirror. Media have been used to disseminate health information and to encourage the adoption of proper health behavior, however over the period, the media has paid more attention to certain disease at the expense of others due to the seeming prevalence and its association to poverty; with Leask, Hooker & King (2010) arguing that the traditional components of mass media- print, radio and television- is in some way "a poor

vehicle for communicating scientifically accurate information about health and medicine due to sensationalism, sins of omission and sheer inaccuracy" on the part of reporters (Leask, Hooker, & King, 2010). Cavaca et al., (2016) in their study, are also of the view that the media tends to neglect certain diseases due to the low newsworthiness of the story and the deprived groups it affects.

In the Ghanaian media, prevalence is given to communicable and non-communicable disease such as malaria, cholera, maternal mortality, hypertension, strokes, cancers, diabetes, eye disorders, and oral health conditions with little to no attention given to rare disease. The coverage of disease in the media are often done with respect to increasing prevalence of the said disease such as sickle cell disease, autism and hepatitis. Unfortunately for other rare disease stories, available research to provide information, expert dialogue as well as prevalence is lacking giving journalists little to no information to pursue rare disease stories; at best, rare diseases stories are covered to raise funds to support persons living with these conditions- a one off gesture that holistically does not achieve much.

1.2 Statement of the Problem

Efforts have been made on a global level to combat the challenges of living with a rare disease, nonetheless other jurisdictions are yet to catch up and garner the same momentum. Studies of rare diseases and media's coverage of such health issues have been done in various jurisdictions across the globe. However, there is a need to understand the outcomes of these studies within the Ghanaian context. Although studies on rare diseases have assessed prevalence, awareness of it by clinicians, treatment options available (Jason, Maxime, & Anne-Sophie, 2021; Glascock, et al., 2018; Moultrie, Kish-Doto, Peay, & Lewis, 2016) among others, very little focus has been given to media's coverage of rare disease as posited by Cavaca et al., (2016). According to their study,

the media shun the coverage of rare diseases such as amyotrophic lateral sclerosis (ALS), leishmaniasis, Down syndrome and verminoses due to the political and economic interest of the newspapers, the editorial line and the organizational routine of the newsrooms (Cavaca, Emerich, Vasconcellos-Silva, Santos-Neto, & Oliveira, 2016).

Initial reviews of studies done in Ghana on disease coverage observed that communicable and non-communicable diseases such as malaria, cholera, diarrhea, meningitis, hypertension, and diabetes were given prominence by the media (Kushitor & Boatemaa, 2018; Smith & Tietaah, 2017; DarkoBonsu, 2015). Some attention have also been given to genetic conditions like sickle cell, childhood cancers, hepatitis and autism albeit at the expense of genetically rare conditions such as spinal muscular atrophy, angioedema, bloom syndrome, cap myopathy, mucopolysaccharidosis and the likes.

This study therefore seek to assess the views of the Ghanaian populace on rare diseases, coverage of it by the media and media's effort in creating rare disease awareness, clinicians' knowledge of rare diseases along with understanding other studies within the context of Ghana.

1.3 Objective of the Study

The objective of this study is to examine the knowledge of rare diseases and suggest alternative ways of increasing its awareness. The specific objectives are to:

Specific objective

- To examine media coverage of rare diseases in the dailies
- To examine the knowledge of rare diseases among a cross section of clinicians
- To examine the knowledge of rare diseases among a cross section of the public

- To assess the coverage of rare disease issues using solutions journalism's framework as a developmental tool

1.4 Research Questions

The following are the research questions:

- How frequent are rare disease stories captured in the dailies?
- How much knowledge about rare disease is available among clinicians?
- How knowledgeable is the Ghanaian public on rare diseases?
- How can rare disease stories be covered using solutions journalism's framework?

1.5 Significance of the Study

Many are the frustrations of families with persons living with a rare disease in Ghana and across the globe; frustrations of diagnostic odysseys, financial wits to be able to secure an appropriate diagnosis, the question of what next after the diagnosis, care coordination, disease management and the quality of life of a person living with a rare disease, the availability of support systems, policies, and including person living with a rare disease on the national health insurance scheme among others are but a few of the facets this study seeks to address. In addition, media's coverage of rare disease in this dispensation cannot be overemphasized. Understanding the motivations and interests of media practitioners in the coverage of stories can shape the course of rare diseases reportage in Ghana.

As more and more studies are being done about rare diseases with the hope of finding treatments to and improving the knowledge thereof of the over 7000 rare diseases out there, this study

contributes to understanding foreign studies within local context and increasing the knowledge of rare diseases locally to create a better informed society that makes informed decisions. Again, the study aims to understand the rare disease landscape in Ghana with respect to prevalence and access to care, media's effort in projecting rare diseases to get the needed attention from the appropriate authorities, contribute to the limited available literature on rare diseases and augment the African sub-region research data on rare disease.

1.6 Limitations of the Study

The study does not foresee any limitations to the study as resource person are eager to volunteer information that will aid the realization of the study objectives. However, timely access to these resource person might be a challenge due to the busy schedules of the study participants.

1.7 Delimitations of the Study

The study focused on the use of newspapers in capturing media's coverage of rare diseases. It identified the Daily Graphic and Ghanaian Times newspapers as appropriate in achieving the objective of the study based on the general notion that these two dailies are the most sought-after and comprehensive dailies within the country. Preference was given to the year 2019 specifically January 2019 to December 2019 due to the absence of COVID-19 within that period and the easily accessible nature of that year's content for the study. In addition, the researcher believes that the period delimited would provide an appropriate reflection of the coverage of general health stories.

Correspondingly, clinicians from the Greater Accra Regional Hospital (Ridge hospital), Korle-Bu Teaching Hospital and Shiloh Medical Center in Accra and Afienya respectively were all selected

as participants of the study as researcher is confident of the knowledge of these clinicians on the subject under study. The researcher is certain that these clinicians can provide the requisite information that would be relevant to achieving the objectives of this study.

Two reporters - a senior journalists with Ultimate FM in Kumasi and a junior reporter from the Daily Graphic in Accra respectively were both interviewed virtually to understand the media landscape along with the motivations that inform story coverage as well as what can be done to increase rare disease awareness and knowledge.

A focus group discussion was had between a cross section of the Ghanaian public to capture their knowledge of rare diseases as pay of the study.

1.8 Organization of the Study

This research is structured into five main chapters. These are the introduction, review of the literature, methodology, interpretation and presentation of evidence, and description, conclusions and suggestions. Chapter one is the introduction that included the context of the study, the problem statement, research goals and questions, study rationale, study scope, study limitation, and study organization.

CHAPTER TWO

LITERATURE REVIEW

2.0 Introduction

The literature review is a process that provides a background context to the phenomenon under study. The review of literature for a particular study provides a deeper understanding of works that have been done by previous researchers and scholars. It enables other researchers identify gaps that require attention and foresight into the area that needs to be studied. The literature review thus provides grounding and context for every research or study.

2.1 Review of Related Studies

2.1.1 Coverage of Diseases

The mass media- print, television, radio and the internet –has an immeasurable reach as a communication mechanism that fuels society's transformation. Society is shaped by the expressions of the media, as it reflects societies and serve as the vehicle that molds the dynamics of society. Media's reach and visibility accords it some prowess that aids the alteration of the societies it operates in and by extension the global village through globalization in adopting proper health behaviors. Cavaca et al., (2016) is of the opinion that "media visibility is a strategy used to legitimize priorities, contextualize realities, and organize and prioritize health problems on the public agenda, making these problems noticeable as concrete demands, specific and independent of the newsworthiness assigned to them by the current mode of news production (Cavaca, Emerich, Vasconcellos-Silva, Santos-Neto, & Oliveira, 2016). Media visibility therefore must be employed

in the daily dissemination of health issues regardless of its newsworthiness as deemed by editorial judgments and motivations of news production such as advertisement.

Regardless, as a medium of communicating health issues, Leask, Hooker & King (2010) are of the view that the components of traditional media is in many ways a poor vehicle for communicating scientifically accurate information about health and medicine, owing to its susceptibility to sensationalism, sins of omission, and sheer inaccuracy (Leask, Hooker, & King, 2010). The Regenstrief Institute buttresses the point by adding that media covers health extensively, but that coverage is not sufficiently nuanced and accurate although media can be a respectable source of information for patients and their families as well as a useful public health tool (Regenstrief Institute, 2021). The media should thus make efforts in training reporters in communicating scientifically accurate information to augment the knowledge of citizens so as to keep an informed society that makes informed decision and contribute to the development of the community.

The coverage of diseases by the media over the years and across the globe have focused on non-communicable diseases such as malaria, cholera, meningitis, diarrhea, cancers, heart diseases, strokes, flus and pneumonia, respiratory diseases, tuberculosis among others (Huffpost, 2012; Kushitor & Boatemaa, 2018). According to Young, Norman & Humphreys (2008), frequency of the coverage of certain diseases in the media skews public perception of diseases since media functions as a critical interface between the scientific community, government, and the public, with a responsibility to strike a careful balance between raising awareness of issues of public concern and irrationally alarming the public at large. In their study, participants considered diseases that occur frequently in the media to be more serious, and have higher disease status than those that infrequently occur in the media even when the low media frequency conditions were considered objectively acute by a separate group of participants (Young, Norman, & Humphreys,

2008). This is the reality of persons living with a rare disease as limited coverage of their diseases inhibits their access to proper care due to the paucity of knowledge within the public's domain leading to a lack of adequate social integration thereby making them a socially isolated and impoverished group who suffer stigma and discrimination on a regular basis.

The use of media to disseminate health information and to enforce the adoption of certain behaviors therefore must be encouraged as an effective strategy to increase rare disease knowledge and awareness among the public to ensure that persons living with a rare disease feel a sense of belonging and become properly integrated into society to contribute their quota to society's development as they tend to be skilled and knowledgeable.

2.1.2 Knowledge of Rare Diseases by the Public

Research has shown that some rare diseases have a more harmful effect on health-related quality of life than other serious illnesses (Shafie, et al., 2020) yet persons living with a rare disease normally, have a paucity of knowledge regarding the disease from which they suffer from. Managing a rare disease can be exhausting for patients and caregivers, owing to limited availability of health, social and financial support. Rare disease patients lack access to adequate treatment as compared to patients with other chronic illnesses (Esquivel-Sada & Nguyen, 2018.). Knowledge of rare diseases among the public is generally low owing to the absence of information on rare diseases and the fact that it is barely discussed among the public (Shafie, et al., 2020). A study conducted by NORD revealed that 50% of patients and caregivers attributed diagnostic delays to a lack of disease awareness (NORD Rare Insights, 2020). There remain public knowledge of diseases that are prevalent as compared to those that are not. Diseases such as cholera, malaria, tuberculosis, cancer, sickle cell disease, hepatitis, autism among others are widely known by reason of its appreciable prevalence. Similarly, diseases such as spinal muscular atrophy,

Huntington disease, spina bifida, fragile X syndrome, Duchene muscular dystrophy have gained a rare status following its low prevalence rate in Ghana. Although sickle cell disease, Down syndrome and autism are rare diseases, they are widely known diseases within the Ghanaian setting.

In view of the limited knowledge of rare diseases therefore, the National Organization for Rare Disorders (NORD) - based in Connecticut in the United States of America -has put together about 350 disease specific advocacy organization working around the globe to augment the knowledge of rare diseases through awareness campaigns such as the Rare Disease day celebration observed every last day of February. The knowledge of most rare diseases is so insufficient that they are also known as orphan diseases because of their failure to attract the interest of researchers, medical specialists, drug makers, and policy makers (Valdez, Ouyang, & Bolen, 2016).

2.1.3 Knowledge of Rare Diseases by the Clinicians

Knowledge of rare diseases among clinicians have been covered by various studies. In a study conducted by Kesari et al., (2005) to assess the knowledge of clinicians on spinal muscular atrophy, the study revealed inadequate awareness among physicians and obstetricians in India led to late referrals for diagnosis. They added that clinicians tend to take a sympathetic approach when counseling patients rather than provide patients with facts (Kesari, Rennert, Leornard, Phadke, & Mittal, 2005). Baynam et al., (2019) posit that many clinicians do not recognize people with rare diseases or are unaware of available resources for advanced diagnosis and treatment. They therefore urged that the issues of rare-disease awareness and genomic literacy be raised among healthcare providers as well as the exchange of best practices to promote the utilization of resources (Baynam, et al., 2019). Similarly, Shafie et al., (2020), in their study mentioned the lack of awareness by healthcare providers, expertise and laboratory support services as a challenge that

often results in misdiagnoses as well as delayed diagnoses of rare conditions, adding that the awareness level among Malaysian physicians about rare diseases is still low compared to their familiarity with other conditions. This they attribute to the scarcity of resources which leads to a shortage of trained medical professional in the area of rare diseases leading them to think that they will barely come across rare disease cases in their career (Shafie, et al., 2020). Studies in China postulate that, with a rare disease population of 16.8 million, it takes on average 5-6 years and three to ten doctors to make a diagnosis with families ascribing delayed diagnosis to the lack of rare disease awareness and knowledge among clinicians (Li, et al., 2021). In Ghana, for example, it takes on average four to eight visits to the hospital to adequately get a diagnosis (Rare Disease Ghana Initiative, 2020)

Furthermore, the lack of awareness of rare diseases is attributable to the lack of a rare disease registry. Quite a number of countries struggle with rare disease cases due to patient's inadequacy to secure a diagnosis owing to diagnostic cost. Due to this, physicians are unable to keep track of suspected or confirmed rare diseases cases so as to streamline training and specialization towards that direction as well as increase public knowledge. As a result of the high cost of diagnosis and the paucity of laboratory expertise in genome sequencing and genetic testing within hospitals, most rare disease patients die undiagnosed or misdiagnosed thereby leading to the underreporting of rare disease cases (Shafie, et al., 2020; Li, et al., 2021).

2.1.4 Solutions Journalism as a Developmental Tool

Journalism has contributed to shaping societies over the years. It is deemed as the fourth realm of the estate with the characteristic of mirroring society. Journalism can be defined as the process of gathering and disseminating information through a channel to an audience. The American Press Institute defines journalism as the activity of assessing, gathering, creating, and presenting news

and information (American Press Institute, 2021). Furthermore, journalism exists to foster a healthier public climate while providing individuals with the information they need to make the best decisions about their lives and societies (Kovach & Rosenstiel, 2001; Rosen, 1999). As mirrors of society, journalists have the responsibility to hold up an accurate mirror to society (Bansal & Martin, 2015). As part of that responsibility, journalists as their code of conduct stipulate, are encouraged to uphold integrity and be mindful of people's right to true information (Ghana Journalism Association, 1994)

The practice of journalism however, has been characterized by the exposure of societies' problems with a lack of an attempt to a solution to the afore-mentioned problems- an inaccurate mirror to society by the media which tends to make problems scream while solutions whisper (Bansal & Martin, 2015). This according to Kinnick, Krugman & Camercon (1996) contributes partly to compassion fatigue in the news media, leaving rare disease patients in a state of despondency owing to a lack of information within the mainstream media.

Due to this, David Bornstein and Tina Rosenberg introduced solutions journalism to curb compassion fatigue and to proffer solutions to society's problems so as to properly mirror societies. To achieve this, David and Tina as well as a team of journalists provided guidelines to identifying or creating a solutions based story:

1. Does the story explain the causes of a social problem?

2. Does the story present an associated response to that problem?

3. Does the story refer to problem-solving and how-to details?

4. Is the problem solving process central to the story's narrative?

5. Does the story present evidence of results linked to the response?

6. Does the story explain the limitations of the response?

7. Does the story contain an insight or teachable lesson?

8. Does the story avoid reading like a puff piece?

9. Does the story draw on sources that have ground-level expertise, not just a 30,000 foot understanding?

10. Does the story give greater attention to the response than to a leader, innovator, or do-gooder?

Stories of this frame they believe can delegitimize excuses for inaction, reimagine the status quo, change a community's conversation and policy, penultimate expose a community to a powerful idea that can transform its impact and ultimately bring more effective strategies to a community's attention (Bansal & Martin, 2015).

2.2 Theoretical Framework

A theory is a set of interrelated concepts, definitions, and propositions that present a systematic view of events or situations by specifying relations among variables, in order to explain and predict the events or situations (Glanz, Rimer, & Viswanath, 2008). Theories set out to describe, analyze, and predict phenomenon to aid understanding; give clarity and logicality to the problem under study and links concepts, variables, and hypotheses. Theories systematically manage knowledge, justifies acceptance or rejection of our curiosity based on their merit or demerit (Chijioke, Ikechukwu, & Aloysius, 2020). Theoretical frameworks demonstrate an understanding of the theories or concept that are employed, relevant to the phenomenon under

study. A theoretical framework is used to limit the scope of the relevant data by focusing on specific variables and defining the specific viewpoint that the researcher will take in analyzing and interpreting the data to be gathered (USC Libraries, 2021). This study therefore employs the following theories to aid the understanding of the concept under study. The researcher is of the view that inculcating these theories into the study would enable readers better understand the dynamics of the study objectives.

2.2.1 Media Bias Theory

There unequivocally remain a bias towards the coverage of rare disease stories mostly owing to the lack of information and the limited interest of journalists within that space. Media owners have political motives as well as profit motives, and can influence public opinion by withholding information that is derogatory to their political agenda - provided that agenda is not too far from the political mainstream. Media bias is the systematic differences in the mapping from facts to news reports which tend to sway readers to the right or left on issues (Anderson & John, 2012). Gentzkow, Shapiro & Stone (2014) define media bias as a partial order on reporting strategies, where loosely speaking a consumer shifts beliefs from the left to the right (Gentzkow, Shapiro, & Stone, 2014). The media tend to focus on things of political and audience interest at the expense of other things that are of social and economic importance. The media bias theory holds that the media possesses power to influence and build an agenda (agenda building), get the public to think about the agenda that was built (agenda setting) and then influence how the public thinks about the issues (framing) (The Research on Media Bias, 2017). The media bias theory hence examines the prejudices of media practitioners in the discharge of their civic duties to the society within which it operates using framing and agenda setting theories.

2.2.1.1 Agenda Setting

The agenda setting theory refers to how the coverage of news by the media determines which issues become the focus of public attention. This is due to the assumption that i) media filters and shapes what we see through its gatekeeping function rather than just mirroring societies to audience and ii) the more attention the media gives to an issue, the more likely the public will consider that issue to be important. Agenda setting is done on 3 levels; 1) policy agenda setting which arises when both the public and the media agenda influence policy making decisions 2) public agenda setting is when the public determines which stories are considered important and should be the agenda 3) media agenda setting occurs when the media deems certain stories of importance and gives it prevalence (Alvernia University, 2018). The core of agenda setting is that elements that are emphasized in the media come to be regarded as important among members of the public. The agenda setting theory does not only focus on getting the public to think about what is going on but how to think about the pictures in our head and by extension what we do. Agenda setting has to do with the transfer of salience from one agenda to the other. The agenda setting effects are the byproducts of the choices the media has, to selects few topics to pay attention to since they lack the capacity to discuss dozens of issues daily nor do audience wish to be overwhelmed with that much information on dozens of topics in a day. Media is therefore encouraged to set agenda that resonates with the public and push the powers that be to act on them (McCombs, 2014).

2.2.1.2 Framing

Framing focuses on conceptual frames that structure an individual perceptions of society through the selection of a particular direction and constructing a coherent story. Frames represent structures which holds together an individual's context of what they are experiencing in their lives as

represented by a picture (McCombs, 2014; Hernandez, 2015). To frame is to select some aspects of a perceived reality and make them more salient in a communication text in such a way as to promote a particular definition, casual interpretation, moral evaluation and/or treatment recommendation for the items described (Entman, 1993). Lipmann in his book chapter- the world outside and the pictures in our head- hold that the pictures are a reflection of the media not necessarily the world outside, therefore the bits that are included or excluded in a news story influences how we see that issue and form opinions about it (Fledge, 2017). This study made use of these frames to better examine the framings in rare disease coverage.

Frames of news focuses on how stories are portrayed by the media in an effort to explain complex or abstract ideas in familiar, culturally resonating terms.

Frame of action centers on the best way to describe actions that might be undertaken by individuals to achieve a desired goal. In other words, frame of actions focuses on persuasive attempts to maximize corporation, necessary to achieve compliance with a desired goal.

Frame of issue result in extensive public discussion and require resolution within the public policy forum, such as a legislature or the court. At the heart of most issues is the question of interpretation that is how a particular problem or concern should be understood or explained since issues are the bases around which publics are organized and public opinions formed.

These theories when applied to the coverage of rare disease stories in conjunction with solutions journalism framework which looks at the coverage of stories with the aim of proffering solutions to it and to reduce the compassion fatigue can change the course of rare disease coverage and give it some prevalence to attract that level of attention it requires. More solutions journalism reporters ought to be trained to seek knowledge on rare diseases in order to whip up interest and augment

the knowledge of rare disease among reporters. Solutions journalism principles should be used to frame media stories and set the rare disease agenda so conversations can be had around it and the plight of rare disease patients brought to bear so action is taken towards resolving them while eradicating media bias towards the coverage of rare diseases.

2.2.2 Social Learning Theory

The social learning theory as propounded by Albert Bandura emphasizes the importance of observing, modelling and imitating the behaviours, attitudes and emotional behaviours of others. The theory considers how both environmental and cognitive factors interact to influence human learning and behaviour. Social learning theory in attaining behavioural change is done through the principles of i) observational learning and ii) meditational process. The observational learning process holds that people especially children observe behaviours around them and imitate same while the meditational process posit that learning is done through a process of attention, retention, reproduction and motivation (McLeod, 2016). These according to Bandura shapes people's worldview and increase their knowledge of the social worlds they live in. What this means to the study is that members of communities should pay more attention to persons living with a rare disease; create mental pictures of the patterns observed (in order to know when something changes); weigh the ability to perform the behaviour demonstrated by the model (pre-empt the behaviour of the patient) and then evaluate the potency to actually perform the behaviour or otherwise (know what to do about the person should anything change). Members of societies therefore constantly must take cognizance of persons living with a rare disease within their communities and create mental pictures of support and acceptance towards such, to reduce the stigma along with the mental health burden that come with living with a rare disease. In addition, members of societies must observe and report unlikely presentations to health facilities as quickly

as possible since early detection of certain rare conditions can aid health practitioners create a proper management plan for such patients.

2.2.3 Social Capital Theory

Social capital theory refers to the collective value of all social networks and the inclinations that arise from these networks to do things for each other. Coleman (1990) defines social capital as any aspect of social structure that creates value and facilitates the actions of the individuals within the social structure such that change in various ways facilitate instrumental action (Seibert & Kraimer, 2001). Correspondently the Organization for Economic Co-operation and Development thinks of social capital as the links, shared values and understandings in society that enable individuals and groups to trust each other and so work together (OECD Insights: Human Capital, 2021). The theory according to Robert Putnam thrives on information, mutual aid or reciprocity, collective action and identity and solidarity.

Thus clinicians should as much as possible endeavor to acquire information on rare diseases as well as create networks and avenues where best to best practices are shared to enable them work together and facilitate instrumental action towards resolving diagnostic odysseys experienced by the rare disease community in Ghana.

2.3 Chapter Conclusion

This chapter reviewed works relevant to this study with the goal of improving the understanding of the study. The chapter discussed media's coverage of diseases, the knowledge of rare diseases among publics and clinicians as well solutions journalism as a concept that when employed by reporters can increase the knowledge of rare diseases within the country Ghana. Unambiguously,

the chapter discussed theories that further support the study and gives the study a better context for analysis.

The next chapter will discuss the methodology to be employed for collecting data for the study, and further discuss the findings of the study.

CHAPTER THREE

METHODOLOGY

3.0 Introduction

This chapter largely enumerates the processes adopted to conduct the study and the research methods employed to achieve the desired objective of the study outlined in earlier chapters. It captures the research approach and design, defines the sampling and sampling technique, data source, data collection method and data collection instrument, data analysis method, ethical consideration and chapter summary.

3.1 Research Approach

The research approach is an effective strategic process that outlines the steps undertaken to narrow broad assumptions while increasing the validity of the research methods of data collection, analysis and interpretation (Creswell & Creswell, 2018). Studies have established the qualitative, quantitative and mixed method approaches as proven approaches employed in every research work. This study thus adopts the qualitative approach as researcher deemed it most suitable to explore and aid the understanding of the phenomenon under study along with the analysis of its outcomes.

Qualitative research is an umbrella term covering an array of interpretive techniques which seeks to describe, decode, translate and otherwise come to terms with meaning, not the frequency, of certain more or less naturally occurring phenomenon in the social world (Van Maanen, 1983, p.9). Similarly, qualitative researches seek to preserve and analyze the situated form, content, and

experience of social action rather than subject it to mathematical or other formal transformations (Lindlof & Taylor, 2002).

Qualitative research likewise involves the studied use and collection of a variety of empirical materials- case study, personal experience, introspection, life story, interview, artifacts, and cultural texts and productions, along with observational, historical, interactional, and visual texts- that describe routine and problematic moments and meanings in individuals' lives (Denzin & Lincoln, 2018). Furthermore, Denzin & Lincoln (1994) describes the qualitative approach as a complex, interconnected family of terms, concepts and assumptions which crosscut disciplines, fields and subject matter (Denzin & Lincoln, 1994). In essence, qualitative studies observe various phenomenon in their natural setting and ascribe meaning to them based on individual perceptions of the said phenomenon.

Following the above, this study believes that the qualitative research approach can aid the researcher draw meanings by decoding, translating and coming to terms with meanings clinicians, reporters and the public ascribe to rare diseases as the study seeks to examine in relation to the objectives of the study media coverage, clinician and public knowledge of rare diseases in Ghana. The outcomes however would not be subjected entirely to mathematical or other formal transformations or interpretation since qualitative studies observe various phenomenon in their natural setting and ascribe meaning to them based on individual perceptions of the said phenomenon.

3.2 Research Design

As part of the processes of conducting a study, the research design is employed as a framework to be used to explore research outcomes. Research designs are types of inquiry within qualitative, quantitative, and mixed method approaches that provide specific direction for procedures in a research study (Creswell & Creswell, 2018). Questions like who or what will be studied? What strategies of inquiry will be used? What tools for collecting and analyzing empirical data would be used; are employed to provide a better understanding of the phenomenon under study (Denzin & Lincoln, 2018). In view of this it is appropriate that every research require a strategy of inquiry since the research design serves as the master strategy to articulate the expected outcomes of the study. Qualitative research designs border on narrative research, phenomenological research, grounded theory and case study (Creswell & Creswell, 2018). This study therefore employs a qualitative research design, with a close look at case studies.

3.2.1 Case Study

Gerring defines case studies as an intensive study of a single unit –a single unit connoting a bounded phenomenon- for the purposes of understanding a larger class of similar units. In order words the researcher aims to investigate and clarify aspects of a larger class of similar present-day phenomena that are not always completely regarded with additional units concealed. (Gerring, 2014).

By the same token, Yin (2018) asserts that case studies rely on multiple sources of evidence which are relevant the more research questions require an extensive and in-depth description of some social phenomenon since social phenomena and context are not always discernible in real world situations.

In furtherance, case studies encompass all modes of enquiry, with its own logic of designs, data collection techniques and specific approach to data analysis (Yin, 2018). The essence of a case studies illuminate a decision; why they were taken, how they were implemented, and with what result (Schramm, 1971 cited from Yin, 2003, 12).

This study therefore employs an exploratory case study approach as the researcher seek to understand the rare diseases phenomenon with respect to its knowledge by clinicians and the public as well as its coverage in the news media.

3.3 Sample and Sample Size

To establish the validity of every study the target group is an important makeup of the research. The target group is often known as the population. The population generally constitute all eligible components of the study out of which a sample is drawn. A sample is a separated quota from the population which enables the researcher to work with a more manageable population due to time and resource constraint which usually hinders the success of a study.

Samples therefore allow researchers to narrow down their scope while capturing the relevant stakeholders who reflect an accurate representation of the population being studied. In contrast, samples are not always representative of the population being studied due to the non-generalizability of research findings as characterized by qualitative studies. This is because, qualitative researchers are inclined to studying relatively smaller populations in detail without producing data that can be subjected to statistical evaluation which is often generalizable.

For the purposes of this study, newspapers from two different news sources namely Daily Graphic and Ghanaian Times were sampled from January 2019 to December 2019. This is due to the

general notion that these two news sources are the more, independent and credible within the Ghanaian setting. Also, the year 2019 was preferred due the absence of COVID-19. The presence of COVID increased health reporting and researcher believes that considering the year 2019 would provide a fair basis to study health reportage in Ghana. Also, three doctors- two senior doctors and an entry doctor along with two practicing journalists- a senior journalist with 20 years of experience and an amateur journalist were sampled for an interview to elicit first-hand information on the status of the rare disease ecosystem. The doctors and journalists were selected based on the researcher's perception of their knowledge and experience that can aid the study achieve its objectives. A focus group discussion with 5 participants was had as well to elicit the public's general knowledge of rare disease. Focus group discussions was preferred based on the advantages it provided the researcher in terms of time and efficiency as participants were not physically accessible. Focus group discussions enabled researcher to sample as many views as possible since it makes room for 6-8 participants.

3.4 Sampling Strategy

The researcher adopted the non-probability purposive sampling technique for the study. Purposive sampling according to Robinson (2014) is the intentional selection of informants based on participants' ability to elucidate a specific theme, concept or phenomenon (Robinson, 2014). Furthermore, Palys (2008) posits that purposive sampling is a series of strategic choices about whom, where and how one does research (Palys, 2008). Purposive sampling aid eradicate the barrier of cost and time constraint as it enables researcher select participants based on researcher's judgment. Participants of the study were thus selected as per the researcher's perception of them,

deeming them as warranting inclusion based on their perceived level of knowledge on the subject matter.

The researcher hence purposely selected two senior medical officer from the Korle-Bu Teaching Hospital as well as the Greater Accra Regional Hospital who have immense knowledge and experiences with persons living with rare diseases and another doctor who had just finished school and about to commence her housemanship. The researcher targeted these groups of doctors to better understand the training processes of clinicians as opposed to their realities on the job and to aid researcher in answering research question two since their line of duty were relevant to that question. Similarly, two practicing journalist were selected purposively to aid the researcher answer research question three which borders on journalistic efforts- application of solution journalism principles- in increasing rare disease awareness among the Ghanaian public. A five-member focus group discussion was had among a cross section of Ghanaians to assess their general knowledge of rare diseases. Lastly, two newspapers were consulted to elicit the frequency of rare disease reportage. The researcher settle on Daily Graphic and the Ghanaian Times as per the notion that those two were considered the most preferred and credible sources of information within the country.

3.5 Data Source

Data sources are classified into two- primary data sources and secondary data sources. The type of source preferred to collect data usually depends on the type of research. Primary data sources in one breathe normally are preferred when much about a phenomenon is unknown and research need to elicit first-hand information to establish a point. Interviews, focus group discussion among other are examples of primary data sources. For the purposes of this study, interviews as well as focus

group discussions were utilized to collect requisite information for the study from study participants. Secondary sources of data in another breath are sources that provide researchers with already available information they can source from to make their case. Secondary data sources serve as the basis to seek and collect further information on the phenomenon under study. Based on the nature of the study, both primary and secondary data sources were accessed to elicit first-hand information on the phenomenon of rare diseases in Ghana.

3.5.1 Primary Sources

3.5.1.1 Interview

Maccoby and Maccoby (1954) define interviews as "a face-to-face verbal exchange, in which one person, the interviewer, attempts to elicit information or expressions of opinion or belief from another person or persons- the interviewee(s)" (Maccoby & Maccoby, 1954). The interview process usually involves two people with the objective to access the thoughts and feelings of study participants on a particular subject (Sutton & Austin, 2015). David Silverman (1993) reiterates what interviews are, adding that interviews allow for an in-depth analysis of a relatively small sample size and places the focus of the research on the views of the participant. Interview ranges from structured, semi-structure and unstructured. The study employed semi structured interviews because it allows the interviewer to remain a listener, withhold the desire to interrupt and occasional ask questions that clarify the story (Brinkmann, 2018).

3.5.1.2 Focus Group Discussion

Focus group discussion is a technique where a researcher assembles a group of individuals- usually 6-8 participants to discuss a specific topic, aiming to draw from them complex personal experiences, beliefs, perceptions and attitudes of the participants through a moderated interaction (Cornwall & Jewkes, 1995; Hayward, Simpson, & Wood, 2004; Israel, Schulz, Parker, & Becker,

1998; Kitzinger, 1994; Morgan, 1996) as quoted by (Nyumba, Wilson, Derrick, & Mukherjee, 2017). Focus group discussion according to Kamberelis and Dimitriadis (2013) diminishes power relations between researchers and research participants enabling participants to collectively interrogate the conditions of their lives to promote transformation (Kamberelis, Dimitriadis, & Welker, 2018).

The role of the researcher in a qualitative study is to attempt to access the thoughts and feelings of the participant by putting themselves in another person's shoes to understand the subjective experiences of participants (Sutton & Austin, 2015). Interviews and focused group discussions thus provided the researcher the opportunity to do just that- access the worldviews of the study participants on the subject to rare diseases and media's effort in improving awareness.

3.5.2 Secondary Sources

3.5.2.1 Content Analysis

Secondary sources such as newspapers were engaged to inquire the frequency of rare disease reportage and to inform interview questions to journalists. As opined by scholars, content analysis at one level can be captured and revealed in a number of statistics, provide a replicable methodology to access deep individual or collective structures such as values, intentions, attitudes, and cognitions and does not suffer from researcher demand bias (Duriau, Reger, & Pfarrer, 2007). Content analysis are unobtrusive sources of information and can be accessed by the researcher at a time that is convenient to the researcher (Creswell & Creswell, 2018).

3.6 Data Collection Method and Instrument

Data collection method is a systematic processes by which data is gathered, observed, measured and analyzed accurately using standard validated techniques known as instruments. Qualitative data collection instruments vary from interviews, ethnography, focus group discussion, content analysis and observation. The research instruments adopted for the study include content analysis, focus group discussion and interviews. The instruments were selected after a careful consideration of the research objectives with the researcher deeming the selected instruments as appropriate to use.

3.6.1 Interviews

Kajornboon (2005) avers that there remain reasons why interviews are a preferred data collecting research instrument. Interviews are useful when there is a need to attain highly personalized data and when there are opportunities required for probing. The interviews were semi-structured and an interview guide was prepared to obtain the required answers and to keep the interview within time. The respondents - doctors and journalist- are greatly experienced in the various field and had very little time to spare. The doctors were selected from the Greater Accra Regional Hospital (Ridge) and the Korle-Bu Teaching Hospital while Journalists were selected from EIB Network (Ultimate FM) and Daily Guide. The interviews lasted between 32 and 50 minutes respectively to draw insight on the scope of rare diseases in Ghana along with ways by which rare disease awareness could be increased in the media space using solutions journalism as an approach.

Lindlof and Taylor (2002) opine that semi-structured interviews are apt for working with small samples and for studying specific situations or supplementing and validating information derived from other sources (Lindlof & Taylor, 2002). The researcher thus booked appointment with the

respondents prior to the day of the interview and secured a venue that provided the right ambience required to elicit the appropriate information. The interviews with journalists was had over Zoom since respondents were in Kumasi and Accra respectively. A senior journalist was unable to join due to her busy schedule. However, that of the doctors were had in their offices within their respective hospitals i.e. Korle-Bu teaching Hospital, Greater Accra Regional Hospital and the Shiloh Medical Center. The semi-structured approach enabled participants the liberty to provide detailed and exhaustive answers to the questions asked them. The interviews were recorded and transcribed via the Otter app installed on the researcher's mobile phone and replayed severally to correct improper transcriptions.

3.6.2 Focus Group Discussion

According to Nyumba et al., (2017), focus group discussions aim to obtain data from a purposely selected group of individuals rather than from a statistically representative sample (Nyumba, Wilson, Derrick, & Mukherjee, 2017). Similarly, focus group discussions serve as a bridging strategy for scientific research and local knowledge (Cornwall & Jewkes, 1995). Furthermore, Berkes (2004) asserts that people's perceptions and their socio-cultural situation is critical to decision-making on natural resources since most people derive their notions, mental constructions and interpretations from their immediate surrounding and develop these from experiential knowledge (Berkes, 2004).

A focus group discussions was therefore had to draw from a cross section of the public, their knowledge and perceptions of rare diseases and ways by which awareness of it could be increased. A focus group discussion guide was prepared to elicit the desired answers from respondents and to work within the time allocated for the discussion. The study employed a single focus group approach and was held over zoom. The discussion lasted an hour and 15 minutes and participants

for the study were carefully selected. Consent was sought and the discussions proceeded. The single focus group approach enabled participants to freely express themselves as researcher's only role was to moderate the discussion.

3.6.3 Content Analysis

Content Analysis enables a rigorous exploration of important but difficult to study issues of interest by examining trends and creating themes. As a result, content analysis aids researcher understand other people's cognitive schemas through the analysis of texts. It also provides a replicable methodology to access deep individual or collective structures such as values, intentions, attitudes, and cognitions. (Duriau, Reger, & Pfarrer, 2007)

January 2019 to December 2019 versions of the Daily Graphic and Ghanaian Times were selected for the analysis. Based on the objectives of the study, the frequency of rare disease reportage were sought for from the years selected. Throughout the search, it was observed that rare diseases were fairly reported in the dailies. The researcher observed that certain "privileged" rare diseases like Hepatitis, Sickle Cell Disease and Autism were frequently reported at the expense of other life threatening rare diseases. Researcher hence sought to find out from journalist why that was the case and to elicit from them ways through which rare disease knowledge could be increased.

3.7 Data Analysis Method

Data analysis is the process of making sense of the data collected for the study. LeCompte and Schensul (1999) explain that data analysis is the process of reducing large amounts of collected data to make sense of them. Thematic analysis was adopted in analyzing the data collected. Creswell (2014) avers that thematic analysis is a type of qualitative analysis used in identifying,

analyzing and reporting patterns (themes) within data. It enables the researcher organize and describe data set in detail; interpret aspects of the study and enhances data management, data reduction and conceptual development. The various data collected through content analysis, interviews and focus group discussions were developed into codes which were later on grouped into themes and analyzed. Thematic Analysis is most appropriate when seeking to discover concepts and ideas and describe human behavior using interpretations (Mark & Yardley, 2004). The study thus aided the researcher to understand the various viewpoints of the respondents on the subject of rare disease awareness.

3.8 Ethical Consideration

Ethical issues considers the privacy of respondents participating in a study. Issues of ethics borders around informed consent, beneficence, confidentiality and anonymity, and privacy. The researcher in the quest of seeking informa0tion did not need to conceal the identities of respondents since the study did not contain any source that could raise ethical issues. Ethical clearance was sought from the Ghana Institute of Journalism to seek respondents' opinion about the phenomenon under study. Informed consent was sought for from respondents to be recorded. Due to the burden of living with a rare diseases, families as well as patients were not considered for the study hence there was no need promising privacy, anonymity and confidentiality for the study. The study objective was explained to respondents and they consented to their expressions being used solely for the academic purpose for which information was being sought.

3.9 Chapter Summary

This chapter delivered the research approach employed for the study. It went further to discuss the research design and how the population was sampled to ensure the study was successfully done. The chapter explained the data collection instruments and procedure used for the study along with a brief explanation on the kind of data analysis plan adopted. The next chapter deliberates the findings and discussion of the study.

CHAPTER FOUR

FINDINGS AND DISCUSSIONS

4.0 Introduction

This chapter captures findings from data collected from study participants with recourse to relevant theories and literature earlier reviewed. The key findings of the study centered on understanding the rare disease ecosystem in Ghana.

The following research questions guided the collection of data and analysis:

RQ1. How frequent are rare disease stories captured in the dailies?

RQ2. How much knowledge about rare disease is available among clinicians?

RQ3. How knowledgeable is the Ghanaian public on rare diseases?

RQ4. How can rare disease stories be covered using solutions journalism's framework?

4.1 Coverage of Rare Disease Stories in the Dailies

The study found that rare diseases were fairly given visibility in the print news media. Juxtaposing the findings to Cavaca et al., (2016) assertion on media visibility, they argue that media visibility as a strategy legitimizes priorities, contextualize realities and prioritize health problems on the public agenda. In this case, rare diseases visibility was considerable low and not adequate to push rare diseases on to the public agenda following the fact that throughout the year only 18 stories on rare disease were covered in the Daily Graphic and 18 in the Ghanaian Times, most of which were same events covered by different media houses.

Although Leask, Hooker & King (2010) are of the view that components of traditional media are a poor vehicle for communicating scientifically accurate information, it turned out that the traditional media particularly print media was an apt vehicle for communicating scientifically accurate information as it provided the space to document accurate information by health practitioners. Out of a total of 36 rare disease stories captured in both the Daily Graphic and Ghanaian Times, the findings were explained in the following themes.

4.1.1 Size of Story

The size of a story determines the importance accorded the story as determined by the newspaper. In the stories identified, 9 stories were captured in full page, 2 stories were captured in more than full page, 8 stories were captured as half page stories, 7 as less than half page, 7 as more than half page, 2 stories were captured as other (less than quarter page) and 1 as quarter page. Generally, researcher observed that rare diseases stories were accorded some importance in the newspaper considering the overall space given to rare disease stories.

The table below gives a representation of the findings:

Table 4.1.1 Size of Story

Size of Story	Frequency	Percentage
Full Page	9	25
More than Full Page	2	6
Half Page	8	22
More than Half Page	7	19
Less than Half Page	7	19
Quarter Page	1	3
Other	2	6
Total	**36**	**100**

Source: Field Data 2021

4.1.2 Type of Story

The type of story sought to uncover from the newspapers which areas of the newspapers covered more rare disease stories. The researcher discovered that out of the 36 stories identified, 22 of them were captured under the straight news section, 6 were flagged as features, 4 were captured in the health section, 3 were opinions and 1 an editorial. Most straight news stories sought to inform or update readers on what advocacy groups especially sickle cell foundation of Ghana were doing to improve access to health for sickle cell disease patients in Ghana. Features and Opinion stories sought to inform and educate readers on rare disease management processes.

The table below gives a representation of the findings:

Table 4.1.2 Type of Story

Type of Story	Frequency	Percentage
Straight News	22	61
Features	6	17
Health	4	11
Opinion	3	8
Editorial	1	3
Total	**36**	**100**

Source: Field Data 2021

4.1.3 Type of Frame

Discussing the frames used in the stories identified, the study discovered that frame of news, action and issues were dominantly used. Of the 36 stories identified, 23 of them were captured as news frames, 12 as action frames and 1 as an issue frame. The types of frames used were earlier discussed in chapter two.

The table below gives a representation of the findings:

Table 4.1.3: Type of Frame

Type of Frame	Frequency	Percentage
Frame of News	23	64
Frame of Action	12	33
Frames of Issue	1	3
Total	**36**	**100**

Source: Field Data 2021

4.1.4 Tone of Story

Under tone of story, the researcher identified affection, call to action and informative as the tones expressed in the stories found. Under affection one story was dominant whereas 23 stories were informative and 12 a call to support a patient in need or a course of action to improve the quality of life of rare disease patients. In all, 36 stories were identified for the analysis

The table below gives a graphical representation of all the findings:

Table 4.1.4 Tone of Story

Tone of Story	**Frequency**	**Percentage**
Informative	23	64
Call to Action	12	33
Affection	1	3
Total	**36**	**100**

Source: Field Data 2021

4.1.5 Angle of Story

The angle of story, looked at what the story sought to achieve. It categorized the angles into i) call to action, ii) awareness creation, iii) advocacy efforts, iv) disease management advice by healthcare practitioners and v) call to support patients. Of the 36 stories noticed, 6 called on government to act on rare disease cases, 13 tabled efforts made by advocacy groups and the government to address rare disease challenges especially that of sickle cell disease and hepatitis, 10 tabled rare disease management processes, 4 appealed for support for rare disease patients and 3 focused on awareness creation.

The table below gives a representation of the findings:

Table 4.1.5 Angle of Story

Angle of Story	**Frequency**	**Percentage**
Call on Government	6	17
Efforts by Advocacy Groups	13	36
Rare Disease Management Processes	10	28
Appeal for Support	4	11
Awareness	3	8
Total	**36**	**100**

Source: Field Data 2021

The period under study identified 36 stories with coverage of about 10 diseases ranging from sickle cell disease, hepatitis, lupus, heart disease, tuberculosis, cancers, autism and glaucoma. According to Huffpost (2012); Kushitor & Boatemaa (2018) coverage of such diseases have predominantly dominated the media space as a result of its prevalence within the Ghanaian community. Young, Norman & Humphreys (2008) are of the view that diseases that are often covered in the media tend to skew public perception of which diseases are actually life threatening and those that are not. In this instance, the diseases captured above in the Ghanaian setting are not entirely rare but have gained much more attention leading the public to think that these are the only diseases that require interventions.

In the data above, although sickle cell, autism, hepatitis, glaucoma and tuberculosis are recognized as rare diseases by the bibliographic data on rare diseases, they are not considered as rare diseases in Ghana considering the weight of occurrence and attention given it by the media. In a focus group discussion for this study, the knowledge of these diseases as rare came as a shock to participants due to its consistency in occurrence and coverage by the media. Diseases that were actually

considered rare in Ghana such as progeria, treacher collins, spinal muscular atrophy, among others were not at all heard of by study participants and often not covered.

4.2 Knowledge of Rare Diseases Available among Clinicians

This research question sought to find out whether clinicians were knowledgeable on rare disease in Ghana as well as understand the healthcare sector in Ghana. This is because, Baynam et al., (2019) posit that many clinicians do not recognize rare diseases and so do not take prompt actions. Similarly, Shafie et al., (2020) argue that the scarcity of resources leads to under trained medical practitioners in the area of rare diseases which makes clinicians think they will rarely encounter rare diseases. It turns out that clinicians in rural-urban areas tend to be quite clueless about rare diseases as opposed to clinicians in urban areas due to the availability of teaching hospitals, referral centers and the exposure to more patients. Discourse with clinicians, on the subject revealed much more than the study hoped to achieve. Three clinicians were interviewed on the subject of rare diseases; the first two were senior clinicians and have practice for years and the third is about beginning her housemanship. The findings from these clinicians were in tandem with the objective of the study. On one hand, the junior clinician had some basic knowledge of rare diseases due to what she had read but has not encountered a rare disease patient. On the other hand, the senior clinicians had a lot of experience and exposed the challenges within the health sector that inhibits the capture of health issues holistically. The findings were categorized into the following themes and discussed accordingly.

4.2.1 The Dynamics of Diagnosis

The dialogue revealed that the principal issue confronting persons living with a rare disease in Ghana is diagnosis. The challenge of diagnosis serves as the bedrock on which every other

challenge rare disease patients face is built. To begin with, most clinicians tend to misdiagnose patients due to the paucity of knowledge of rare disease and the familiarity with certain types of rare diseases. For example, most children with neuromuscular disorders here in Ghana are flagged as cerebral palsy patients during their initial prognosis. Consistent visits to the hospital therefore becomes the order of the day for such patients until clinicians are out of options and refer cases to teaching or regional hospitals at a point where conditions have deteriorated. This back and forth to the hospital in trying to get a diagnosis results in what is called diagnostic odysseys- the long and winding journey to securing a diagnosis- leaving patients and families frustrated and feeling helpless.

Also on the issue of diagnosis, it was discovered that there exists no genetic laboratory as well as geneticists in the country to provide genetic services like genetic counselling which can go a long way in reducing the rare disease burden since the populace will be better informed to make more informed decisions with respect to the choice of partners. On the part of genetic testing laboratory, for every patient that require a genetic test to secure an accurate diagnosis of the condition from which they suffer from, they would have to wait for three to four weeks to receive results of the tests conducted since all genetic testing is done overseas.

The long waits for results often leads to loss of life. Although clinicians cannot confirm the numbers, the discourse revealed that most children who frequent the hospital with a suspected rare disease die undiagnosed in a short period of time due to the nature of rare diseases- degenerative and life threatening. A number of children do not live to witness their test results or their fifth birthday.

Also, children die undiagnosed sometimes due to the unaffordability of genetic tests. Parents and families with rare diseases sometimes lose their children due to the unavailability of funds to

actually run genetic test after a doctor's prognosis of a suspected condition. On average, a genetic test costs between GHS 1500- GH 10,000 depending on the condition and the diagnostic processes involved. Families usually are unable to afford such costs and so return home without ever knowing the condition that claimed their child's life.

Newborn screening offers an opportunity to diagnose conditions more quickly and at an early stage to better inform families as to which management processes to adopt. According to research newborn screening have saved 12,500 children. However, in Ghana newborn screening is not as comprehensive since it capture only sickle cell disease patients. Clinicians bemoan the lack of widespread screening for diseases as common as congenital hypothyroidism and fetal alcohol syndrome.

Aftermath of diagnosis. The discourse revealed that families that are able to afford diagnostic tests after securing a diagnosis get stuck with the results as the health care systems are not adequately structured to manage rare diseases. Depending on the type of disease, families of patient's do not have access to treatment options. This is because most rare diseases do not have a cure but require multidisciplinary approaches to manage- a system which is expensive to access with parents expending resources out-of-pocket to manage the disease which can be financially daunting. Services like physiotherapy, occupational therapy, speech therapy and dietician services are all provided for out-of-pocket by families- an approach which is not financially sustainable to family resources.

4.2.2 An Under-resourced Healthcare System

The senior clinicians bemoaned the primary nature of the healthcare system along with the prevalence of infectious, communicable and non-communicable diseases as inhibiting further access as well as cater for complex demands of healthcare needs for rare disease patients. There is

therefore the need for government to take bold steps in investing in genetic testing services along with an infrastructural upgrade of regional hospitals to sub specialist hospitals and train clinicians accordingly to serve the needs of the rare disease community at large and prevent patients from ending up in prayer camps.

Correspondently, clinicians acknowledge the limited knowledge of rare diseases among themselves especially pediatricians, urging that the healthcare system be structured in such a way that more healthcare practitioners -priority given to pediatricians- be trained in different fields of specialization especially in rare diseases through seminars and lecture in medical schools to reduce the burden on clinicians to know and do everything. They explained that very few clinicians were interested in rare genetic diseases due to its unattractive nature, clinician recommend that the space be made more attractive to encourage clinicians to venture into that space adding that medicine is a lifelong practice and clinicians cannot know it all.

4.2.3 The Lack of Registry and Care Coordination

On the issues of a registry, the doctors stressed the need for a diagnosis arguing that without a diagnosis, a registry cannot be created. They however hinted that the only registry that is currently available is that for sickle cell disease because they have a diagnostic program running adding that 2% of the Ghanaian population are diagnosed with sickle cell disease annually (Asare, et al., 2018)**.** On the issue of care coordination, clinicians reasoned that the lack of appropriate care for disability will greatly improve following the creation of sub specialized hospitals to effectively coordinate care for rare disease patients.

4.2.4 The Call for Policy

On policy, the clinicians suggested the creation of a policy for children with disability as well as the expansion of the newborn screening program to accommodate other rare diseases to detect

early children with rare conditions so as to commence management processes to sustain patients. Again, clinicians make the case for the inclusion of rare disease management onto the national health insurance scheme to relief parents and families of the high cost of managing rare diseases. Lastly, the importation of rare disease medications they reasoned should be procured by government to reduce the burden of cost on families since these medication are produced out of the country and are very expensive.

4.2.5 Increased Advocacy

Advocacy by parents support groups using the Rare Disease Day phrase "leave no one behind" they believe is apt in attracting the powers that be to act, as efforts by clinicians to secure the needed structures to aid person with rare diseases have proven futile.

4.3 Knowledge of Rare Diseases among the Ghanaian Public

Shafie et al., (2020) acknowledge that knowledge of rare diseases among the public is generally low owing to the absence of information on rare diseases and the fact that it is barely discussed among the public. The study observed that there was an appreciable level of knowledge of rare diseases although participants were unaware of autism, sickle cell disease, hepatitis, and epilepsy as rare diseases due to its high prevalence within the country. The findings under this research question are categorized below.

4.3.1 Under-reporting of Rare Diseases

Participants of the study were of the view that the knowledge of rare diseases were generally low and will only be known when it affects a person close to them. For example every participant in the study at one point in time had come across a person living with a rare disease and that is how

come they came to know about rare diseases. Aside that, participant got to know about certain rare diseases because certain prominent people in Ghana were affected by it and the story was carried by the media. The discussion however revealed that the knowledge of diseases that are considered rare by the bibliography data on rare disease are not particularly rare in Ghana, yet participants only had knowledge of such disease. Consensually, participants were of the view that the knowledge of diseases that are actually rare were limited in Ghana.

4.3.2 Unavailability of Genetic Diagnostic Facilities and Registry

Participants were of the view that due to the unavailability of diagnostic facilities in the country leading to high diagnostic costs, if diagnostic costs were reduced, more and more undiagnosed person could be tested and the rare disease population known. This way, a comprehensive registry can be created to inform policy interventions that can shape the public knowledge of rare diseases as well as improve the quality of life of persons living with a rare disease.

4.3.3 Communication to Eradicate Stigma and Discrimination

Participants were of the view that the nature of rarity of a rare disease accords it currency. In other words, due to the rarity of diseases, it has the tendency to gain prominence in the media. They therefore suggested that communication by health practitioners in connection with the media using behavior change communication processes can effectively improve knowledge and reduce if not eradicate the stigma and social isolation that persons living with a rare disease experience.

4.3.4 Encourage Open-mindedness

Participants lastly admonished that the general public be supplied with adequate information to encourage a positive attitude, be more receptive of rare disease patients and broad-minded in accommodating persons living with a rare disease as they are equally very intelligent and can contribute meaningfully to society if given the enabling environment to function.

4.4 News Coverage of Rare Disease Stories Using Solutions Journalism's Framework

Solutions journalism's framework holds that for a news item to be able to solve society's problem and reduce compassion fatigue, it must satisfy the condition of explaining the cause of a problem, present an associated response with a how to detail, explain the limitation of the response, draw lessons from the story, avoid hailing a person but the solution and seek local expertise in resolving the challenge rather than import solutions that will not resonate with solving the problem. Journalists are urged to capture news items in consideration to this framework but that is usually not the case. On the contrary, journalist in Ghana raised concerns as to why rare diseases are rarely covered by the media let alone employ the solutions approach to report these stories. Their findings were themed below:

4.4.1 Media Dynamics

Rare disease stories are not one that journalist set out to look for due to the limited knowledge of it as well as the lack of audience interest. Journalist from the interview observed that due to the varying demands of the economy, the issue of health particularly rare diseases tend to be at the bottom of the media conversation as opined by McCombs (2014) that the media cannot talk about everything in a day. Unfortunately in our setting the issue of politics, economy, social issues and entertainment take preeminence over everything else. This overtime has reduced audience interest and contributed to the limited knowledge of rare diseases within the public space.

A nonexistence of a holistic health desk in the newsroom and the overwhelming demand of primary health issues contribute to the limited reportage of rare diseases. Journalists are of the view that there exists in theory not in practice a health desk. What this means is that most media houses do not have adequate health reporters and a dedicated health desk to cover health related stories holistically. Again, they are of the view that the very few health reporters are overwhelmed

with the coverage of non-communicable and communicable diseases giving them less time to pay attention to rare diseases.

The dynamism of the Ghanaian media space, journalist avers preempt a careful posture in discussing certain issues as managers of the media have political interest that must be fulfilled. Discussing certain social issues tend to weaken the political prowess of a government and so journalists tend to shy away from conversations such as those on rare diseases except when discussed by experts. They therefore recommend that more disease experts begin conversations that would increase knowledge and interest to save them also from "offending" the political interests of their owners.

4.4.2 Lack of Diagnosis, Registry and Information

Journalist assert that the lack of registry to understand the gravity of rare disease to inform conversation on rare diseases adds to the problem of limited information. They make the example of COVID, malaria, cholera, diarrhea and how they have gained prominence. They reason that these diseases have gained prominence in the media because of available statistic in the public domain. Due to the rarity and lack of a registry to track rare diseases and develop interventions, journalist tend to at best run stories as one offs to appeal for funds to supports persons living with a rare disease.

Journalists again bemoaned the limited information on rare disease and encouraged more research into rare diseases to provide them with adequate information to educate the populace since the lack of area specific information cripples effort to increase rare disease knowledge among the populace. This they say limits general interest of rare disease among the public.

4.4.3 Non-existent Funding for Publicity and Drug Development

Inadequate funding and coordination for rare diseases is another concern that was raised. Journalist opined that funding for rare disease education in the media space is nonexistent as compared to other diseases such as malaria, breast cancer and the likes. They therefore recommend the involvement of adequate stakeholders such as the ministry of health, NGO Committee on Health among others in the quest to draw attention to rare diseases.

Limited drug development efforts by institutions due to the limited numbers of rare disease patients and the inability to recover drug development cost has made rare disease management expensive and non-lucrative for drug development institutions.

4.4.4 Tradition and Superstition

Tradition and superstition they reason contributed to the under reporting of rare disease cases. Most parents tend to be ashamed of their wards with a rare disease and often throw them away because of society's stigma. In one of the experiences they shared, a family with a rare disease patient (hydrocephalus) in the north were banished from the community due to the belief that the child is cursed. These beliefs and practices prevent patients from seeking medical help and in the long run undertake outrageous ventures that marvels society and clinicians.

4.4.5 Policy and Advocacy

The need for advocacy through schools journalist assert can go a long way in improving rare disease knowledge as student will become ambassador who will educate their parents on rare diseases. Collaborative efforts between the Ghana education service, the ministry of health and health institutions as well as the media is the way to go. Increased expert engagement, seminars, positive noise to improve knowledge and awareness of rare disease is another suggestion that journalist made.

Lastly they mention the need for a strategic plan for rare diseases. The journalists are of the view that a policy on rare disease research, communication and management as well as an incorporation of rare disease education in the antenatal structure would empower women and by extension families to seek help as early as possible to avert discrimination and social isolation.

4.5 Chapter Summary

This chapter enumerated the findings and discussions of the research questions for the study. The first objective sought to identify the frequency of the print media's coverage of rare disease and was tackled by grouping all its findings in the following themes; size of story, type of story, type of frame, tone of story and angle of story. The second objective which sought to uncover how much knowledge of rare diseases was available to clinicians had its findings categorize as follows; the dynamics of diagnosis, an under-resourced healthcare system, lack of registry and care coordination, the call for a policy, increased advocacy. On the third objective of assessing how knowledgeable the Ghanaian public is on rare diseases, findings were grouped in the following themes: underreporting of rare diseases, unavailability of genetic diagnostic facilities and registry, encourage open mindedness, communication to eradicate stigma and discrimination. The fourth and last objective that sought to assess how rare disease stories can be covered using solutions journalism's framework, were themed as follows; media dynamics, lack of diagnosis, registry and information, non-existent funding for publicity and drug Development, tradition and superstition and policy and advocacy. In all very interesting findings were observed and the researcher captured them accordingly.

CHAPTER FIVE

SUMMARY, CONCLUSION AND RECOMMENDATIONS

5.0 Introduction

This chapter summarizes the findings of the research, draws conclusions and finally makes recommendations on the importance of increasing rare disease knowledge among the public, clinicians and the media.

5.1 Summary

The study sought to examine rare disease awareness in Ghana among clinicians, the media and the public as well as how solutions journalism framework can be employed to increase rare disease awareness. The significance of the study is that it would deliver a better understanding of the rare disease landscape and draw stakeholder's attention to the predicament of persons living with a rare disease in Ghana.

The review of literature on the various objectives served as a foundation for exploring further the phenomenon under study. The media bias theory which encapsulates the agenda setting and framing theories were used to conceptualize research question one. Research question two and three were contextualized using the social learning theory by Albert Bandura and social capital theory respectively. These theories stated the need for societies to learn more about rare diseases and to put in place structures that create value that facilitate action.

The research approach and design for the study were qualitative (Creswell, 2014) and case study (Yin, 2009) respectively. The participants of the study were purposively selected based on their appositeness to the phenomenon (Palys, 2008). The data analysis method used was thematic

analysis (Creswell, 2014) where the data was categorized into codes and was later grouped into themes. This method of analysis enabled the researcher to vividly present the findings according to the objectives of the study.

5.2 Main Findings

The first objective of the study sought to examine the frequency of rare disease reportage in the print news media. The study discovered that rare diseases were fairly reported in the print news media. A maximum of 36 stories were recorded in both newspapers- Ghanaian Times and Daily Graphic- over the one year period under study. In each newspaper four types of diseases were primarily dominant. In the Daily Graphic, sickle cell disease, childhood cancers, hepatitis and autism were captured; in the Ghanaian Times, glaucoma, sickle cell disease, hepatitis, tuberculosis, autism and lupus were recorded. It was discussed that the amount of space dedicated to rare disease reportage was generally appreciable and showing some commitment on the part of print news outlets on the subject of rare disease. Although covered by the print news media, all the diseases captured with the exception of lupus and childhood cancers were not considered rare in Ghana. Furthermore, it came to light that the tone of the stories were generally informative and educative; the angle of the stories aimed at creating awareness, providing advice on disease management, a call on government and benevolent bodies to act on rare diseases and support patients, and advocacy efforts by advocacy groups.

The second objective which sought to assess the knowledge of clinicians on rare diseases discovered that clinicians in rural urban areas generally possessed limited knowledge on rare disease as compared to clinicians in urban areas. Clinicians in urban areas acknowledge that fact and suggested a number of interventions that can augment clinicians' knowledge of rare diseases

and reduce misdiagnosis which often deteriorated rare disease cases. Again the study discovered that clinicians in urban areas lacked appropriate tools to work with and to improve the quality of life of rare disease patients since most of the health facilities were under resourced to properly manage patients. The researcher discovered that diagnosis was a huge challenge in the rare disease space and very few patients could afford it, leading to loss of life and a population of undiagnosed patients. There was also an unavailability of genetic testing laboratory and geneticist in the country making rare diseases expensive to diagnose since all samples must be sent abroad for testing. A comprehensive policy for children with disability as well as on newborn screening and an inclusion of rare disease management on the national health insurance scheme the study discovered would go a long way in improving rare disease management within the country. It turned out that increased advocacy on the part of families of patients can go a long way. Lastly, the researcher discovered that the availability of diagnostic services will greatly contribute to the creation of the rare disease registry and improve coordinating care for such patients since there would exist a synchronize data to reference and to create the necessary interventions to improve the overall health of patients.

The penultimate objective, aimed at assessing rare disease knowledge among the public revealed that the Ghanaian public was generally knowledgeable of rare disease and had at least encountered a patient at one point in their life. However, the public was of the view that rare diseases were underreported due to the limited knowledge of it and the fear of being stigmatized. Also, the unavailability of diagnostic facilities as well as sub specialist hospitals left families spending hugely on rare disease management. The knowledge of certain rare diseases as constantly publicized in the media it turned out were not rare at all as it was really common in Ghana except for the fact that genetic testing were not being done to pool the disease population and to know the

disease burden so as to create efficient interventions to manage them. Attention was also drawn to the general public on being open-minded and accommodative of rare disease patients because these patients face two battles- the illness itself and dealing with a world where only few people understand what they are up against.

The final objective had as its goal utilizing solutions journalism as a developmental tool in covering rare disease stories to reduce compassion fatigue and to empower communities to take initiative and act on rare diseases. The study discovered that rare disease stories were not stories that journalist intentionally looked out for but chanced on from time to time. Journalist therefore took time to enumerate media's dynamics with respect to rare disease coverage. The first issue raised was the limited time with varying issues to discuss ranging from politics, economy, social and entertainment. Issues of health except when the numbers are high are often relegated to the background and not typically paid attention to. It was also discovered that due to the political terrain of the Ghanaian media space, most media houses are owned by politicians, journalist therefore are careful in discussing certain issues in the public domain to avoid offending its owners. It was also discussed that the inability to assess data and the unavailability of a registry on rare disease makes it difficult to pursue rare disease stories effectively. Again the issue of funding for publicity was discussed as a motivational factor that influenced a lot of inactions in the media with respect to rare disease. Funding they observed contributes to lot of changes leading to the influx of certain information viewers are overwhelmed with. Traditional beliefs and superstitious practices journalist concur limits the quest for more knowledge on rare diseases leading wardens of rare disease patients to dispose of such children with the thinking that they are cursed children. Lastly, policy and advocacy was discussed as the silver lining to easing the burden on rare disease patients.

5.3 Conclusion

This study sought to assess the knowledge of rare diseases among clinicians, the media and the public. It also sought to assess the use of solutions journalism in the coverage of rare disease stories.

The study concludes that knowledge of rare disease amongst the groups studied was generally low. The knowledge of disease that were actually rare was non-existent among the media, public and some clinicians except a few clinicians who had grasp of rare diseases. All subjects for the study concluded that more needs to be done within the rare disease space to increase knowledge, keep a registry, create policy interventions along with diagnostic facilities as well as upgrade hospitals to sub-specialist hospitals. Quite a number of theories- media bias theory, social learning and social capital theories were employed to proffer contextualization to the phenomenon under study.

5.4 Limitation of the Study

The study sought to assess the knowledge of clinicians, the media and the public on the subject of rare diseases. The study generally did not encounter much limitations due to its newness. All participant were willing to volunteer information to increase the knowledge of rare diseases. However, area specific data to support the study was very limited due to the paucity of research on the subject of rare diseases within the African sub-region. The literature reviewed was from Europe and America. Again access to newspapers for the study stalled posing a limitation to the study because the library went on recess for a week. Some clinicians were also quite hard to get due to their busy schedules. There is notwithstanding enough room to study the subject of rare diseases in Ghana.

5.5 Recommendations of the Study

The rare disease ecosystem across the globe is growing. Rare diseases need to be studied extensive to increase knowledge, reduce stigmatization and improve the quality of life of persons living with them. The study therefore makes the following recommendation:

1. Clinicians with a wealth of knowledge on rare disease must begin to engage the media and educate the public on issues of rare disease
2. Researchers within the country should focus attention on studying the rare disease space to provide adequate area specific information to increase rare disease knowledge
3. The study again recommends that rare disease appropriate policies and interventions be made available to persons living with a rare disease in Ghana to increase their quality of life.
4. Bold steps must be taken to invest in genomics to reduce cost of genetic screening as well as improve newborn screening since human genomes have now been mapped and the future of medicine would hinge on genomics. A blood sample can predict future disease which will be useful for planning purposes in our population.
5. Efforts must be made to train clinicians in genetics to provide genetic services to increase knowledge and hospitals upgraded to sub specialist hospital to reduce diagnostic odysseys, provide access to treatment and improve management of rare diseases and eventually prevent loss of life.
6. Funding should be made available to the media to publicize findings from research studies to increase knowledge

7. Efforts must be made to develop a rare disease registry to reduce the instance of underreporting and to inform future planning efforts.
8. The study again recommends that parents and families of persons living with a rare disease must be strong, step out, share their stories and advocate (make positive noise) on the subject of rare disease

5.6 Suggestion for Further Studies

Future researchers may do a study to assess the perspectives of persons living with a rare disease and their families to better understand the rare disease dynamics. Particularly with respect to how they manage rare disease patients in the absence of all appropriate logistics. Following the passing of the resolution for rare bill by the United Nation, researchers can make enquiries into government interventions to remedying the rare disease burden at their local level. Again further enquiries can be made into the media space to facilitate the use of solutions journalism as a developmental tool for the promotion of rare disease knowledge.

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APPENDICES

i. Interview Guide for Journalists

Introduction key: Thank you for making time to do this interview with me today. As established, my name is Esmeralda Arvo-Quardoo, an MA student from the Ghana Institute of Journalism studying Development Communication. I am currently undertaking a study on the topic "Solutions Journalism as a Developmental tool in Increasing Rare disease Awareness in Ghana".

Purpose: I would like to elicit your views on the above topic and strategies you believe can be employed to mitigate the challenges PLWRD face.

Duration: I do not intend to take much of your time, I expect this interview to be done in the next 45 minutes.

Process: I would be taking notes, but the interview session would be recorded as well just in case I missed anything. Excerpts of this interview would not be divulged to any unconcerned third parties but would solely be used for this academic purpose.

Signature of consent: Journalist consented to do the interview

Questions

- What would you describe as a rare disease?
- How often do you think they occur?
- Have you encountered a person living with a rare disease?
- Why have rare disease stories failed to receive cognizance in the media?
- Have health reporters failed society?
- What in your opinion contributes to the underreporting of rare diseases in the media?

- What can journalists do to increase rare disease awareness?
- What strategies can be put in place to increase the knowledge of rare diseases?
- As a journalist, how can you contribute to broadening the knowledge of rare disease?
- Are journalists trained using a multidisciplinary approach to not overlook some of these concerns?
- What sustainable multidisciplinary plan would you suggest be used to train journalist to reduce the rare disease burden?
- What do you know about solution Journalism?
- Do you see yourself as a solution journalist?
- What role can you envisage solution journalist can play in relation to rare diseases in Ghana?
- In your opinion, how can the principles of solution journalism be used to address the rare disease issues in the country?
- What challenges do you foresee impeding the realization of the strategies stated earlier?

ii. Interview Guide for Doctors

Introduction key: Thank you for making time to do this interview with me today. As established, my name is Esmeralda Arvo-Quardoo, an MA student from the Ghana Institute of Journalism studying Development Communication. I am currently undertaking a study on the topic "Solutions Journalism as a Developmental tool in Increasing Rare disease Awareness in Ghana".

Purpose: I would like to elicit your views on the above topic and strategies you believe can be employed to mitigate the challenges PLWRD face.

Duration: I do not intend to take much of your time, I expect this interview to be done in the next 30 minutes.

Process: I would be taking notes, but the interview session would be recorded as well just in case I missed anything. Excerpts of this interview would not be divulged to any unconcerned third parties but would solely be used for this academic purpose.

Signature of consent: Doctors consented to the interview

- What would you describe as a rare disease?
- Is there a definition for the African sub-region?
- What would it take to get a national or regional definition specific to the African setting?
- In your estimation, how frequently occurring are rare diseases in our setting (Ghana)?
- Does Ghana have a rare disease registry?
- How comprehensive is the newborn screening program in Ghana? Does it capture every child and every disease?
- What are the challenges that fraught persons living with a rare disease in our setting?
- What systems have been put in place for coordinating care for persons living with a rare disease?
- Are our hospitals fit to run genetic tests?
- How can the challenge of diagnostic odyssey be resolved?
- What effort have been put in place for clinicians to increase their knowledge of rare diseases?
- Are there rare disease experts in Ghana?
- What will be your final words to the:

a. Public

b. Clinicians

c. Government

iii. Focus Group Discussion Guide

Today's discussion will focus on the Ghanaian public's knowledge of rare disease. My name is Esmeralda Arvo-Quardoo an MA student of the Ghana Institute of Journalism undertaking this study and I will be your moderator for this discussion.

To begin with:

- What words or phrases come to mind when you hear rare diseases?
- How familiar are you with rare diseases or persons living with a rare disease?
- What elements will you consider in a rare disease definition?
- Can you share an experience of a rare disease management processes?
- What options are available to a rare disease patient in Ghana?
- Should rare diseases be covered by health insurance?

iv. Content Analysis Coding Guide

Q1. Name of Newspaper?

1. Ghanaian Times

2. Daily Graphic

Q2. Story Title

Q3. Date of Publication

Q4. Page Number

Level of prominence Daily Graphic and Ghanaian Times give to Rare

Disease stories.

Q5. Story Type:

1. Straight news

2. Special Feature / Feature

3. Editorial

4. Column

5. Opinion

6. Letter to the editor

7. Health

Q6. **Story Size**

1. Full page

2. More than full page

3. Half page

4. More than half page

5. Less than half page

6. Quarter page

7. Other

Q7. **Placement of the story**

1. Front Page (Lead)

2. Front Page (Other)

3. Back page

4. Center spread

5. Other

Q8. Headline size

1. Banner

2. Strapline

3. Single deck

4. Double deck

5. Other

Q9. **Enhancement Type**

1. Photograph

2. No visual

To find out the type of frame used in each story

Q10. Type of frame

1. Framing of issue

2. Framing of news

3. Framing of actions

Tone of stories by Daily Graphic and Ghanaian Times newspapers

Q11. Tone of story

1. Informative

2. Call to action

3. Affectionate

Q12. Angle of story

1. The stories outline advocacy groups and policy makers' efforts towards rare disease issues in Ghana

2. The stories seeks financial support for rare disease patients

3. The stories provide information and/or clinical advice on rare disease management.

4. Create awareness on rare disease issues

5. Call on government and organizations to act on rare disease issues