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Memorable Messages in BRCA-positive Disclosures

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MEMORABLE MESSAGES IN BRCA-POSITIVE DISCLOSURES

by

Alyssa Cam

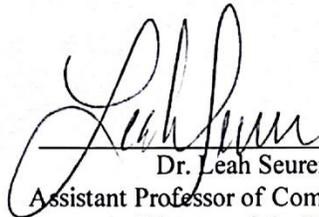
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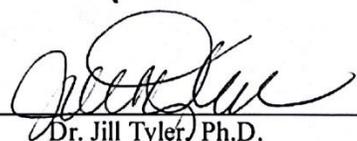
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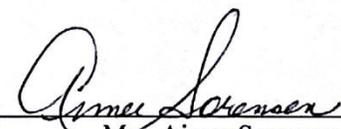
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ABSTRACT

Memorable messages during BRCA-positive disclosures

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Communication in healthcare involves sensitive topics and memorable messages that can impact the way an individual handles a tough situation. Genetic testing for illnesses, like the BRCA gene mutation, creates a time of uncertainty leading to difficult conversations. Communication behaviors contribute to recalling messages of importance that shape future actions. Support and compassion are significant characteristics in messages when encouraging preventative behaviors and aiding in decision-making. This study investigated common themes of memorable messages in BRCA-positive disclosures by collecting data from 123 individuals who have experienced a positive BRCA diagnosis. Memorable messages from healthcare workers, loved ones, and coworkers or acquaintances were qualitatively analyzed. This guided identification of distinct characteristics and common themes in memorable messages from different support networks. Positive, supportive, and compassionate messages were frequently found from loved ones. Educational and supportive messages were prevalent from healthcare workers. Supportive messages from coworkers and acquaintances were frequent but other unexpected themes were also found. These results enrich the study of memorable messages, enhancing the understanding of communication behaviors; while also, encouraging appropriate words to be used in interactions during times of uncertainty.

KEYWORDS : memorable messages, BRCA, health communication, support, genetic counseling

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Introduction

Each day humans communicate by sending and receiving information. There are different forms that it may take, but communication as a whole is a universal concept that connects people's lives together. The words and messages that a person hears everyday while communicating may stay with them and create an impact in their life (Knapp, 1981). Some messages will become memorable and stay with a person for an extended period of time (Knapp, 1981). This is especially apparent in terms of healthcare. There is constant communication and relaying of information between individuals.

The way a healthcare worker shares information can make a major impact on their patient's response (Smith et al., 2009b). When communicating about an individual's health status and in particular about one's genetic information, there is often risk information being shared, that potentially not only affects the individual but also their family (Chopra & Kelly, 2017). Family history and inclusion plays a significant role in genetic counseling for genetic and hereditary mutations. Genetic counselors disclose sensitive information to their patients, and this can create difficult decision making for their patient.

One area within genetic counseling that is increasingly popular is testing for the BRCA1 and BRCA2 mutation (Resta, 2019). The BRCA mutation is a hereditary gene mutation that increases one's possibility of breast or ovarian cancer (Lynch et al., 1997). Testing began to rise because of the effect a BRCA mutation could have on a person's reproductive abilities and shape the family involved. A genetic counselor will have to tell the patient if they are receiving positive or negative test results and the way this is

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communicated impacts how the patient feels and reacts to their diagnosis. A patient that tests positive for a BRCA mutation will have to face many decisions about preventative behaviors and treatment (Puski et al., 2017). This start of a journey can be a long process that is greatly influenced by the support system of the patient. Their support system can be made up of healthcare workers, family, friends, and the media; however, the messages an individual receives during these difficult times can shape a patient's outlook and actions (Smith et al., 2009b). A message with empathy, compassion, and support can lead to positive attitudes and behaviors toward the time of uncertainty (Willer, 2014).

Little research has been done on the messages that BRCA positive patients remember. There has been previous research done on memorable messages and the influence they have on patients. Willer (2014) found that compassionate messages from doctors can enhance patients' experience and create a positive environment. Research done by Smith et al. (2009a) on BRCA patients found the memorable messages from their close family influence emotions and reactions. The previous research has shown that memorable messages are important to patients facing difficult times. The way families, friends, the media, and healthcare workers communicate will shape future behaviors.

This study focused on the memorable messages that BRCA positive patients received from the people in their life when disclosing information. The goal of the study was to find common themes in memorable messages from healthcare workers, friends/family/partners, and coworkers. The following review of literature will describe some of the specifics in the process of genetic testing. Then the literature review will go in-depth explaining the BRCA gene. Next, studies involving communication within genetic counseling from the patient relating to healthcare workers and their families are

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examined. Finally, this essay will discuss memorable messages and how they affect a patient going through times of uncertainty like a BRCA positive test result before describing the purpose of the current study and research questions the study sought to answer.

Literature Review

Genetic Testing Procedure

Genetic testing and counseling are on the rise for many individuals that are concerned about hereditary cancer. Genetics were first introduced into the medical world in the early 1940s. In 1969, the first genetic counseling program began with the United States being the first country to form a specific genetic counseling profession (Ormond et al., 2018). Since its initial start, there are now around 7,000 genetic counselors helping with patient education around the globe (Ormond et al., 2018). The profession is the most well developed in the United States, Canada, the United Kingdom, and Australia. Initially, genetic testing was used to look at reproductive issues (Resta, 2019). It quickly became a growing profession shaping the world's genetic services. With genetic services on the rise, testing is becoming a more complex task than it has been in the past. There are several forms of tests that a person may go through.

There are multiple gene panels or targeted testing that a patient could have to get their genes tested (Doherty et al., 2015). When testing for hereditary breast cancer, a patient can do a multi-gene panel that include the BRCA1 and BRCA2 gene. When a patient is being tested the provider can choose how many genes should be tested and whether it is a panel for only BRCA, a 6-gene panel, or an even larger panel. If it is a

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panel for only BRCA1 and BRCA2, only two genes will be tested. On a 6-gene panel it would usually be BRCA1, BRCA2, TP53, PTEN, STK11, and CDH1; each testing for heredity cancers or other duplications or deletions. A multi-gene panel can be as many as a provider may see fit for the patient's needs (Doherty et al., 2015). Breast cancer can have multiple hereditary cancer predisposition syndromes; however, genetic testing for the BRCA1 and BRCA2 mutation have previously been the most common. Testing for a single gene has been changed to testing for a multi-gene panel for hereditary breast cancer. Multiple gene test and single targeted tests can be useful. Single-gene testing will only look at the genes that are of the main concern (Doherty et al., 2015). Multi-gene panels can aid in decisions for primary and secondary prevention strategies and aid in making decisions about future treatment (Pollard et al., 2020). In addition, the extended panels can be helpful when there may be features from multiple hereditary cancer genes (Oliveira et al., 2021). When getting tested through multi-gene or extended panels that can test for other variants, some genes may or may not have larger significance in the results.

Testing can bring forward many decisions and concerns for a patient. It is important for proper and affective communication to take place when discussing testing and results to testing. Considering genetic testing creates a lot of uncertainty in a patient and this has to be addressed when talking about the risks (Aasen & Skolbekken, 2014). Genetic testing comes with many unknowns that may create future questions and concerns. A few examples of risk information that should be looked at are inheritance, personal risks, futures tests, potential diagnosis, and future treatments (Michie et al., 2005). Inheritance would include looking at how the gene may have been passed down in

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the family and the likelihood of passing the gene onto any current or future children. Personal risks are conflicts or issues that one may have with themselves after getting tested; this may include questioning of oneself and blaming themselves for future inheritance. Potential diagnosis means that the test could be positive, and the patient is at a higher risk for breast cancer, the test could come back inconclusive and give no real answers, or there could be a gene test positive that was not expected. Future tests and treatments would take place after a positive diagnosis. A patient will have to look into what needs to be done to prevent breast cancer if they are BRCA positive. When considering getting gene tested it is important to be educated by a professional specialized in genetics. Getting gene testing should mainly be utilized by a professional that has experience and knows the proper way to communicate risks with patients (Klitzman et al., 2013).

There are many reasons a patient may decide to get their genes tested. Some patients will get tested because they believe that the test results will give them a definitive answer (Zhong et al., 2021). Patients may receive testing for the BRCA genes because a close family member has had breast cancer. Family concerns is the primary reason that an individual may get genetic testing. Tests may give a person an answer that they were looking for and help guide them in future decisions. A patient may also want to be tested in hopes of a negative result, this could help resolve uncertainty that they may be facing about their health.

Undergoing genetic tests can come with errors and risks that many are not aware of if it is not communicated correctly. An accurate assessment of risk needs to be done through creating a family pedigree during a consultation before getting testing done. A

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counselor will tend to map the family history in the form of a pedigree to address the risk of knowing. This is done through two-way communication between the patient and the counselor (Aasen & Skolbekken, 2014). This pedigree needs to be as accurate as possible to aid in the decision whether or not testing is necessary for a patient (Mahon, 2017). Another potential for decision making and error is looking at what test may be needed for an individual. This is where the multi-gene or single targeted gene is considered. Testing can be expensive, and it is good to avoid more testing in the future if it is not necessary (Mahon, 2017).

Finding out the results of genetic testing can create future implications for family members that may lead to more testing for others in the future (Mahon, 2017). Before being tested a patient will need to decide how the sharing of information may go for them. There needs to be an assessment of barriers to effective communication between patients and providers and between patients and their relatives (Pollard et al., 2020). When these barriers are found, a patient can look at how to relay information to their family and present supplemental information to their genetic counselors. Techniques to support decisions can promote accurate information, increase physician-patient interactions, clarify the differing values, and aid in decisional conflict and satisfaction (Pollard et al., 2020). Patients that get their genes tested need to be prepared for discussions with their family about the steps for the future (Pollard et al., 2020). This attitude and knowledge for a patient can help create a line of communication that can help them in the future.

In sum, genetic testing can be a lengthy process from beginning to end. A patient first needs to sit down with a genetic counselor and discuss their family history, reason

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for testing, and any concerns that they may have. Benefits and risks will also be assessed before any further action. Once this conversation is had a counselor decides whether a person should receive testing. The type of test is also determined; whether it should be a panel with only BRCA1 and BRCA2, a 6-gene panel, or multi-gene panel. If testing is given there is a lot of risk and uncertainty that can come with it. After finding out the results of the tests patients have different routes that they can take. Positive results may lead to future testing and treatments to prevent breast cancer and having to talk to family about what this may mean to them. If the test is negative a patient can be done with genetic testing or choose to have a larger panel tested.

BRCA Gene

For the purposes of this study, it is helpful to understand the BRCA gene and why it is important. The discovery of the BRCA gene for scientist occurred in October 1994 leading to genetic testing for BRCA1 and BRCA2 in November of 1996 (Resta, 2019). It quickly become popular because of the potential effects that this gene could bring to reproduction. The BRCA gene mutation is responsible for breast and ovarian cancer in an individual. This also include hereditary breast and ovarian carcinoma (HBOC) and mutations due to non-genetic factors. The mutation can increase the risk that a person is at for cancer in the future (Lynch et al., 1997). Breast cancer is one of the most common forms of cancer and a leading cause of death among women. In the women that are dying from breast cancer, 5-10% are due to hereditary breast cancer (Mavaddat et al., 2010).

The BRCA gene can be separated into BRCA 1 and 2 mutations, but they have many identical by descent (hereafter IBD) germline mutations. This type of mutation is

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hereditary and easily passed down to offspring. IBD also implies that both the BRCA1 and BRCA2 are identical in most ways. When finding IBD it is good to use mutational screening and estimate when the founder mutation arose. The mutations are dated based on the level of linkage disequilibrium (LD) between linked markers and the diseased allele. LD looks at the correlation of differing alleles on the same chromosome to find where there may or may not be abnormalities linked to certain populations. Then there can be a phylogenetics method in place to estimate the age for the most recent common ancestor (MCRA) for the BRCA gene mutation.

A phylogeny tree is created to see the lineage of the gene and what common ancestor carried it. (Marroni et al., 2008). During the research, the BRCA 1 mutation is mainly looked at because the germline mutation on chromosome 17q is known as BRCA 1 and this plays into a large amount of HBOC (Ford & Easton, 1994). When looking at the phylogeny tree, a major origin of the BRCA 1 mutation is from the European ancestry due to the high prevalence of it in the population after European colonization (Tuazon et al., 2020). Marroni (2008) assumes that BRCA1 showed up in alleles at least thirty generations ago, about 750 years. Knowing where the origin is aids in finding the start of the mutation if it is hereditary.

The genetic risk for breast carcinoma increases when it is hereditary and depending on how many close relatives have breast cancer it can continue to increase the risk of being a carrier of the BRCA mutation (Lynch et al., 1997). An individual may have the genetic factors with breast cancer but there may also be non-genetic factors playing into the increased risk. A few examples of non-genetic factors would be alcohol intake, body mass index, reproductive history, and physical activity. However, when it is

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in a family it tends to cluster – keep in mind a shared environment would have a similar affect – and then the familiar relative risk (hereafter FRR) can be examined. The FRR is the ratio of the risk of disease for a relative of an effected indivial to that for the general population. This ratio can range for many reasons but is a productive way to look at the risk for a carrier of the BRCA gene mutation (Mavaddat et al., 2010). Recently it is thought that family history is a strong risk factor for mutation carriers and that cancer risk varies by the location. This suggests that genetic counseling on an individual level would be good to look at both family history and mutation location (Kuchenbaecker et al., 2017).

If an individual is a carrier for the BRCA mutation, there are many risks that they could face. The risk for the BRCA 1 mutation carriers to develop breast cancer by 8-years old was 72% and BRCA 2 mutation carriers is 69%. Looking at ovarian cancer, BRCA 1 carriers have a 44% chance of having cancer by the age of eighty and BRCA 2 carriers have a 17% chance. As a person ages the chance of cancer increase rapidly until it reaches a plateau. BRCA 1 carrier reached a plateau around 31-40 years and the BRCA 2 carriers plateaued about 5-10 years later than BRCA 1. However, there is still an increased breast cancer risk for both carriers when there is an increasing number of relatives that have or had breast cancer (Kuchenbaecker et al., 2017).

Now, with a general idea of the BRCA gene and its risks it is important to look at the previous research on the experiences that go with it. Many times, doing a genetic test is encouraged by outside forces to find out more information of this potential risk. This is especially true when there may be a factor making the individual at a higher risk (Chopra & Kelly, 2017). Getting tested for the BRCA gene is a big decision for many.

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Before being tested an individual has to look at what getting tested for the BRCA mutation could result in. There could be a positive, negative, or inconclusive result.

These responses may trigger emotional responses that were not expected, and the individual must be aware of this. Many times, close relatives will get tested and one will be negative and the other positive. This can create tension between the two because the negative person may experience survivor's guilt. This means that the negative person would feel like they may deserve the bad news more or feel regretful for not having the mutation (Lynch et al., 1997).

Being diagnosed with the BRCA genetic mutation can be life changing because there is a threat of cancer for the remainder of the patient's lifetime. Many times, when this news is brought to the surface there are many negative effects that can come with it.

The idea of getting tested can calm an individual because it is believed to reduce uncertainty after finding out the results. However, depending on those results it may cause an increase in uncertainty because of the new situation (DiMillo et al., 2013). Uncertainty can tend to go along with fear, lack of control, and the feeling of helplessness. This can lead to potential depression or anxiety because the circumstances are unknown. However, on the other side there could also be a feeling of relief. If one tests negative, they know that they do not have to face the fears of cancer. Also, if there is a positive result it may tell the patient what the next step and what actions to take to prevent the onset of cancer. Knowing this information has helped reduce uncertainty in some cases.

A woman that wants to get tested must also take into consideration their age. If it is a young woman getting tested, there needs to be consideration of their future regarding

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children. If a test is done early and comes back positive the individual may have to undergo surgery to prevent cancer. However, this may affect the ability to have children one day (Werner-Lin, 2008a). The news of a positive results would potentially affect the future life plans. It may make the timeline of life feel a lot shorter than before. The timing of the test is crucial to how a patient may react or what they may consider a risk. The results of the test may become their responsibility to inform others and there may be a need to protect other family members from the genetic predisposition (Young et al., 2019). Younger adults that have the carrier will tend to place more weight on the thoughts and opinions of those around them (Werner-Lin, 2008a).

The positive results of a BRCA mutation affects the patient and the whole family (Liede et al., 2002). It can be a difficult battle for the individuals to be a part of because of the unknowns that come with it. If there is a positive test result the individual might have to share it with their family, and it can create more worries for everyone. However, the older a person is the more likely they are willing to share the information with others (Chopra & Kelly, 2017). These results are attached with fear and anxiety that hang over the family for an extended period of time.

An individual may feel a lot of guilt when being positive for the BRCA mutation. This feeling grows with time because this gene could be passed down to their children and there would be self-blame about the potential future outcomes (Lynch et al., 1997). This guilt is also seen when there is a possibility of death due to cancer. A BRCA positive person has great concern for leaving a spouse behind; while the spouse is afraid of losing their loved one (Liede et al., 2002). Fear arises on both sides of the situation. Another issue that follows a positive result for predisposed cancer is insurance

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discrimination. A person carrying the genetic mutation could struggle with their insurance and this needs to be considered before getting tested. There can be fear of changing policies or being denied certain policies due to having a genetic predisposition. Numerous people do not want to face this struggle because there is not a great solution for the issue (Lynch et al., 1997).

The diagnosis of the BRCA genetic mutation can lead to many adaptations in a life that need to take place after recognizing the concerns and potential future. Over time patients learn to adapt and control the stressor because it becomes a daily part of life. The predisposition does not mean that there is cancer, but many take it this way and see it as a crisis (Samson et al., 2014). To decrease this worry it is good to adjust everyday life by going to appointments, educating themselves, and seeing what the positives may be from finding out about the predisposition. Negative psychological effects tend to take place at the beginning (DiMillo et al., 2013). However, with time a patient experiencing testing and having the BRCA mutation can ease this by learning from their experiences (Samson et al., 2014). There needs to be coping skills and a good support system to help get through the adjustments and learn from their experience.

The BRCA gene has become more common since the discovery of it in 1994. The gene is extremely hereditary and heightens an individual's risk for HBOC (hereditary breast and ovarian cancer). An individual's family history can play a key role in the likelihood of carrying the gene and getting diagnosed with cancer in the future. Being tested for BRCA can result in many paths. Having a positive result means that cancer could be in the future for this individual. Then the necessary steps would need to be taken to lower the chances. However, the timing of these results may affect the impact. At a

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young age this may lower the possibility of children. At an older age, the gene may be passed down to children and require more family communication on the circumstances. Having a positive result can lead to tough times for the individual and their family. Communication in genetic counseling can play a significant role in how the interaction works and how the information is shared. A genetic counselor collaborates with the patient and communicates a lot of new information about the BRCA gene.

Communication in Genetic Counseling

As a genetic counselor is having a conversation with a patient, they must look at many different aspects of their communication such as paying close attention to the words and attitude that they may be using. The conversation between patients and professionals should include plain language to help provide opportunities for patients to learn and make informed decisions about genetic testing (van der Giessen et al., 2021). The use of simpler language by counselors and professionals allows patients to interact more and have a better understanding of the information being shared. Research shows that patients may be making decisions without fully understanding the risks so it is important to have the two-way communication and present the information in a way that can be understood (Michie et al., 2005). This is another uncertainty and risk that the patient must face when getting tested and the counselor will have to explain the next steps in this situation. Being on the same level of understanding can result in shared decision making because physician and patients can better manage the uncertainty levels (Zhong et al., 2021). In addition, testing can result in multiple variants that have an

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uncertain significance. This means that there is not a sufficient enough of data to decide if the change in genetic material will cause and issue or not (Mahon, 2017).

Counselors bear many burdens and struggles while communicating before and after genetic testing regarding support of their patients and frustrations with the results of tests (Pollard et al., 2020). Some patients may come in with optimistic views, which is beneficial for the beginning point for the consultation. In research, it suggests that a positive outlook about the situation can shield against future anxiety (Wiering et al., 2013). Along with optimism, a counselor can show more reassurance to help decrease post-visit anxiety. Anxiety and depression tend to be higher before the results of the test are released and decrease over time after the results are shared (Oliveira et al., 2021).

Affective communication used in patient-physician relationships help with the accuracy of risk perception. The patients awareness of the risk associated with cancer will impact how much anxiety and depression is experience after receiving results (Oliveira et al., 2021). It is important to have a conversation before testing about what the counselees are anxious about and whether or not they believe that they are at high risk (Wiering et al., 2013). Having this conversation creates a stronger relationship and can aide the counselors when interpreting and describing test results to the patient.

The results can lead to distress and frustration in patients when their counselor is explaining the situation (Zhong et al., 2021). The patient needs to receive proper education and extensive consolation after receiving results. This is essential to the patient's decisions about their test results and making sure that they can fully maximize the benefits and minimize the future risks (Lerman et al., 1996). The genetic risk will also lead to concerns with the individuals family and the risk of transmission of the mutation

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to future children (Oliveira et al., 2021). Receiving genetic testing can result in a lot of future decisions for the patients and genetic counselors are expected to help with this situation. There is a lot of communication and information sharing that needs to take place for testing to be effective and efficient.

The communication and information being shared can create significant memorable messages for the patient to take in. Genetic counseling should be a family or patient centered process to help aide the patient in understanding and receiving memorable messages that will influence future behaviors (Mendes et al., 2018). This approach is beneficial to creating positive attitudes and coping. When faced with difficult times positive and supportive memorable messages can be a coping mechanism for many (Kaufmann et al., 2021). Positive coping during an uncertain time can evoke hope, resilience, and empowerment. These factors can encourage effective management of the situation during the uncertainty time (Kaufmann et al., 2021). Facing times of uncertainty can lead to patients finding hope to create a positive force in their life. This hope can provide positive coping styles for the patients and their families. Hope can be talked into a situation through memorable messages (Merolla et al., 2017). Previous research shows that memorable messages are a way to introduce positive or negative responses.

In addition to family and professionals, a patient with concerns about their genes and health may turn to health communication in the media. This media is giving recipients memorable messages regarding their genes and health (Parrott et al., 2008). The media is giving out messages regarding genetic testing with direct-to-consumer (DTC) advertisements. These ads are encouraging patients to seek additional tests or medications regarding their health. DTC memorable messages have been affecting the

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decision-making process of individual regrading genetic testing (Parrot et al., 2008).

Cancer, like the BRCA gene, is seen as one of the most common health risks that can be inherited. This contributes to more risk communication and education for the public and patients. Since there is this elevated risk a BRCA patient is more likely to seek help, and this will affect the memorable messages that they are taking in (Knapp et al., 1981).

Messages in breast cancer patients motivate them towards detection or prevention behaviors, this can be important to help decrease the occurrence of breast cancer and potentially save lives (Smith et al., 2009b). However, when a message comes through interpersonal communication it will likely have a greater meaning and influence on behavior rather than messages from the media. Smith et al. (2009b) found that interpersonal communication with healthcare professionals have the largest influence on breast cancer patients. Professional messages show a greater increase in detection behavior and a decrease in patient's prevention behaviors. Genetic counselors are able to pass on many memorable messages that may influence an individual's behavior (Aasen & Skolbekken, 2014) . This risk communication has to look at the patients previous experience and education to form messages that will be received well based on the patient's past.

The previous experience of a patient will also affect how they will respond to a message about breast cancer (Lerman et al.,1996). Education of a patient can have a role in how they react to memorable messages. In Smith et al. (2009a) a patient that had personal experiences with a family or friend with breast cancer has a higher likelihood of citing and reacting to memorable messages. Patients with no connection or experience to breast cancer can still recall memorable messages, however, it is a lower rate. The

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amount of previous exposure to breast cancer can shape what messages are memorable and influence future behaviors. The role a family plays in a breast cancer patient is important to how memorable messages affect a person's attitude (Smith et al., 2009a). Kaufmann et al. (2021) suggested positive and negative memorable messages contributed to the actions of patients and the attitudes.

Reacting to a message includes several emotions that are associated with behaviors and action tendency. Several common emotions in breast cancer patients found by Smith et al. (2010) were anger, fear, sadness, hope, and relief. Anger tends to be associated with problem-solving actions, but the research showed that it was not a common emotion in the diagnosis. Anger was not usually invoked by a memorable message, so it was not seen as factor affecting the behavior of patients after receiving a message. Sadness can be seen in memorable message, but it does not contribute to action very often. Many will feel a desire to shut down or ignore a situation if a memorable message invokes sadness. Fear is an emotion that has gained attention for the actions it can encourage. It is connected to an increase detection actions (Smith et al., 2010). Hope is an emotion that can create action depending on the circumstances. According to Merolla et al. (2017, p. 474), "Hope might be one factor that shapes the storage and activation of memorable messages in people's minds." It can contribute to action behaviors because it can be seen as positive coping strategies. Hope can lead to an individual feeling of in control of the situation. Relief tends to be an emotion that is an after effect of action behaviors. Finding relief in a memorable message does not tend to cause action. Messages that invoked relief tend to occur after there was a positive change (Smith et al. 2010).

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Patients that have been diagnosed with the BRCA mutation face many uncertainties and have to face future decisions. The memorable messages and communication practices that they interact with can have an effect on what they experience after and during their diagnosis. Messages can contribute to the emotions and behaviors that patients have. Family, friends, media, and healthcare professionals – like genetic counselors – are all senders of message and relay memorable messages that shape the receiver. The amount of support and compassion included into the communication process can influence how the information is shared.

Support and Compassion

The diagnosis of the BRCA mutation can be hard on a patient. It is an in-between that is difficult to understand because of the amount of uncertainty there is (Mendes et al., 2018). The patient does not get diagnosed with cancer but now know that they are more susceptible to cancer compared to others. This diagnosis comes with a lot of difficult decisions that will have to be made throughout time. Risk communication and management plays a part into how a patient may deal with the BRCA mutation. Family, spouses, friends, online relationships, healthcare workers, and support groups all play a role in the decision-making process (Puski et al., 2018). It is necessary for patients to have a good support system and feel the compassion and empathy of others because they are being exposed to a lot of new risk.

Families, including partners, play a major role in the support system that a patient has. Family and friends can be a form of informal social support (Werner-Lin, 2008b). A family is there for the patient and tends to participate in many of the decision-making

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processes that a patient may face. This relationship has to have effective communication skills that aid in the conversation of risks and anxiety towards bad news (Datta et al., 2017). Genetic testing and receiving the diagnosis is a family experience that results in facing complex issues (McKinnon et al., 2007). Members in a family tend to be psychologically close to a patient compared to others in the patient's social network. A patient tends to be more willing to share emotions and thoughts with their family members.

Genetic testing can directly impact the spouse of a patient because there are heavily involved in the decision-making process (Liede et al., 2002). A spouse or partner can be a crucial part of a support system when an individual is facing a tough diagnosis or illness. There is meaning attached to a partner and how support is expressed. If an individual feels that their partner is responsive to their emotional needs through listening and affection there is fewer depressive symptoms. In addition, the individual going through the illness will feel that they are valued and heard, making them more likely to feel supported (Fekete et al., 2007). For many patients going through BRCA testing, their partner can become a major support system. It is important to feel valued and appreciated during this time of uncertainty.

Research has shown a supportive family can have a positive impact on woman with breast cancer. There have been better health outcomes – physically and emotionally – and a better ability to cope and adjust to the situation (Yoo et al., 2014). A family providing support can be a beneficial and difficult experience. Having support from family can make the decisions making easier, but it can also put pressure on a patient to

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make a particular decision. When there are un-pleasant support systems a patient may feel alone and exclude their family from the process (Puski et al., 2018).

In addition to family there are other ways of finding support as a BRCA carrier. A BRCA patient may seek support from support groups, web-based chat forums, genetic counselors, and workshops put on by healthcare professionals (Hughes & Phelps, 2010). Going to healthcare professionals is important to learn more information about the risks and guidelines for prevention and screening. Professionals, like genetic counselors, are a main source of support for formal information. According to the literature, a patient that is able to see a genetic counselor have had a better understanding of the risks, screening protocols, and clinical trials (Werner-Lin, 2008b). Carriers tend to cite genetic counselors are their main source of support (Liede et al., 2002). Physicians play a large role in this decision-making process since they are able to provide management plans and recommendations for future steps. A healthcare professional is able to know the risks and needs to efficiently communicate how the risks and uncertainty may impact the carriers life.

A genetic counselor is able to have a positive conversation with the patient and give them the support they need when discussing the diagnosis. If this conversation is done correctly a patient can leave the interaction feeling reassured, supported, and validated (Puski et al., 2018). These formal support systems made up of healthcare professionals are good to relieve some uncertainty but are not always the most efficient in emotional support like a family may be. The interactions can feel more technical then supportive if there is miscommunication or certain messages given during the discussion (Werner-Lin, 2008b). A professional should create family-centered healthcare to help the

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patient face these difficult conversations with their loved ones (Mendes et al., 2018). A family-centered approach can bridge the gap that patients experience when communicating the risk to their family. A professional can help educate the support system of the patient and enhance the care and compassion that a carrier may need (Mendes et al., 2018).

Both family and healthcare professionals-such as genetic counselors-can be primary forms of support for a carrier of the BRCA mutation. This support is necessary to help reduce uncertainty and make a patient feel valued (Fekete et al., 2007). Approaching this support with compassion, empathy, and sympathy can lead to a positive interaction and create a solid support system (Jeffery, 2016). However, it is important to recognize that there can be drawbacks to these forms of support. It can be difficult to communicate with a family and there may be many barriers contributing to this. A family may not support a decision or become distant after learning about the BRCA mutation (Young et al., 2019). The same idea is similar with genetic counselors. They are beneficial to a carrier's support system but have to approach the discussion with compassion.

Emotional support can help individuals deal with their diagnosis and create a better physiological and psychological health. However, emotional support can be a difficult action. It may not be received the correct way and create more distress for the patient. Emotional support like this can be problematic and make a patient feel that the people around them are minimizing their stress and worries. Support should make a patient feel validated and affirmed (Fekete et al., 2007). Compassion should be included when providing support – this should be coming from both the family and healthcare professionals. Having compassion means that the patient's struggles and suffering is

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being recognized to help lead to future actions. In addition to compassion empathy should be used. Showing empathy is the ability to be aware of and experience another person's emotions. This is similar to sympathy; however, sympathy is the realization of an individual going through something bad. Expressing sympathy toward a person shows that there is a mutual feeling (Jeffery, 2016).

When a patient is making hard decisions and is met with compassion and empathy from their support system there can be a release of suffering (Cameron et al., 2015). There is a desire to help and commitment to alleviate suffering that reflects on a person's need maintain and create social relationships (Jeffery, 2016). For compassion to be meaningful it needs to include recognition, emotional resonance, and action toward alleviating suffering (Cameron et al., 2015). These steps can show patients that they are cared for and valued.

Empathy is another aspect that can deepen the interactions a patient has with their support system. It can be addressed through affective, cognitive, moral, and behavioral actions (Jeffery, 2016). Affective empathy is affectively matching the emotion that someone may be going through, a doctor may express the same emotions as the patient when discussing disappointing results. This would allow the patient to feel that the doctor has the same emotions as themselves. Cognitive empathy is being able to look at the patients perspective in an objective way. This is a more detached form but shows patient-oriented perspective. A doctor is able to see from the patients view and understand the patient's feelings. Moral empathy is an internal motivation to help another person and relieve the suffering. This may be done by caring for the patient or giving extra support to help take away some of the pressure. Behavioral empathy is communicating the

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understanding of emotions and acting on them. One would be able to enter another person's experience, while still being aware of their own and not basing the circumstances on their own experiences. This empathy and compassion should come from different support systems – like the counselor, family, and social groups – after receiving testing.

The patient, family, and professional are important aspects to create a positive environment and productive support system. The proper communication between all of them is an important aspect to providing good care during difficult times (Datta et al., 2017). When communication is taking place patients may take in significant memorable messages. The way that a message is worded with compassion and empathy can influence how a patient responds. A memorable message that is formed from a place of support and compassion can leaving a lasting impact on an individual's attitude during their struggles with the BRCA gene.

Memorable Messages

These interpersonal interactions between patients, their families, and genetic counselors are usually face-to-face or through a virtual video communicating verbal messages. When this communication takes places it is leaving an impact on the people involved. Any communication that is taking place during this time has a major role in how the patient may feel about the diagnosis and themselves. Genetic counselors, family, and other support groups are the people that a patient will rely on for information and communication to aid them through this time of uncertainty.

Many times, these messages while communicating are stored temporarily; however, there are select messages that will stay in long term memory and have a major

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impact on an individual's life (Knapp et al., 1981). These influential messages are referred to as memorable messages. Knapp et al. (1981), introduced memorable messages and encouraged research and studies of context surrounding memorable messages. When a message is memorable it had a specific importance to the recipient. A memorable message is impactful based on the receiver, sender, channel, and context of the situation (Knapp et al., 1981). In addition, the sender of a memorable message tends to be a credible and trusted source creating a greater influence on the recipient. Smith et al. (2009b) suggests that breast cancer patients tend to receive memorable messages from healthcare professionals, media sources, friends, and family.

Knapp et al. (1981), identified four main characteristics that a memorable message has when reported that affects the memory process of the message. First is if the message is personally involving. The subject has a connection to the message and is able to relate the idea of the message. Second is that the message takes place when during an outreach for guidance. A person is looking for advice and help to get through their situation. A third characteristic is the sender has importance to the receiver. This important send could be an older or wiser person like a professional or family member. The final characteristic laid out by Knapp et al. (1981), is that the message is structured in way that is easy to remember. The message being sent is structured and presented in a way that is memorable to the listener. It is a simple and short structure that is easy to remember. Repeating a message will also increase the likelihood of it being memorable (Knapp et al., 1981). Memorable messages can become extremely important to individuals that are facing hard times in their lives. Many studies look at how memorable messages are affecting someone during difficult times.

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Memorable messages can be seen as a way of socialization because of the communicative characteristics associated with it. Miczo et al. (2018) connected memorable messages with control theory in terms of relational transgressions. It was found that when memorable messages are recalled in relationships they often are evaluating a partners action and attempting to understand the action. Past studies of memorable messages and their relationship to the receiver focus on the content of the message and the form or context of the message (Merolla et al., 2017). Looking at the content involves looking at the main ideas and thoughts that are provided in a memorable message. If one looks at the forms, it is investigating how the message is structured and relayed. Droser and Seurer (2020) found that the connection between a message and grief represent different impacts of how the recipient responded to a message. Understanding another's actions can influence self-behaviors and decision making. Decision making is a major aspect to genetic testing and genomic health. With these decisions and relationships being formed it brings a time of uncertainty.

The study of memorable messages in the medical field covers many areas of healthcare, genetic counseling being one of them. Miczo et al. (2018) recognized that some memorable messages had transgression or hurtful meanings to them. There were a few categories that they found in the messages: personal responsibility, acceptance, and treatment of self and others. He found that the messages guided courses of actions. Similarly, Smith et al. (2009b) studied memorable breast cancer messages and their impact. She found that messages are able to influence behavior when they are recalled from memory long after initial exposure. Even after a lot of time has passed messages can impact how are person acts. Women perform protected breast cancer behaviors

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differently depending on the messages that they have experienced. The themes Smith et al. (2009b) recognized were detection, awareness, treatment, and prevention of diseases. These messages came from media, healthcare professionals, friends, and family. However, healthcare professionals had the largest impact on future behaviors. Both studies found messages can be an influential part to decisions and actions. Good and bad messages lead to a patient future behavior.

In Willer's study (2014), she looked at women's infertility related to memorable messages. In her work, there were five categories of compassionate memorable messages: offering hope, privileging the patient ahead of the self, practicing patient-centeredness, empathizing, and nonverbally communicating. She found that the compassion used in messages related directly and indirectly to stressors with fertility (Willer, 2014). Compassionate care and messages given to patients can help reduce suffering during treatment. Parrot et al. (2015) looked at how the media displayed memorable messages about genomic health to the public. The study found that many times the messages about cancer and family were the most memorable. In addition, most messages that could be recalled tended to be emotion laden. The more personal and emotional aspects stood out to people. The two studies above recognize the emotion that can be played into messages. When there is a compassion and empathy it can positively impact a patient and reduce suffering.

As mentioned previously, healthcare professionals can have a large impact on how a patient responds to their diagnosis. If a medical professional reacts to their patient with compassion, support, and empathy like mentioned in Jeffery (2016) there is going to be a positive reaction. Smith et al. (2009b) shows the importance and impact of

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healthcare professionals' messages. These characteristics are key players in memorable messages. They can shape how the receiver wants to respond and how they may feel about the situation. Compassion and empathy are also prevalent in Willer's (2014) study. She emphasizes the affects that compassionate messages can have on a patient's treatment behaviors.

Memorable messages can also be used to find hope and attitudes towards a situation. Willer (2014) shows this with her study. Memorable messages with compassion and kindness were able to make a situation brighter and less painful. This can give patients a sense of hope and good to look forward to (Merolla et al., 2017). When needing hope people will tend to rely on positive messages and experiences to keep the difficult times easier. He also touches on the agency of the message. If a person is looking for hope in a memorable message they are more likely to find it and use it to their advantage. In times of uncertainty people with hope may recall the positive memorable messages.

To review, memorable messages can come from family, friends, media, healthcare professionals, coworkers, and more. However, the supportive communication in these messages can create meaningful impacts on a person. The way that the messages is remembered can influence decisions and behaviors of the patient. It may encourage or discourage certain actions. In addition, it could relieve some of the suffering or create more depending on the support and compassion in a message. The times of uncertainty are shaped through the interactions a patient has with others and the memorable messages that they experience.

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Loved ones, like family members, are major place of support for a person with the BRCA mutation. The way a loved one talks about the diagnosis can shape how a patient sees their situation. If a message is made out of a place of support and compassion the patient may have a better outlook on their situation however, the good messages may not always be the memorable messages. In addition, the patient may feel more comfortable with their future decision. Memorable messages and communication during genetic counseling interactions between counselors and patients can also impact what a patient feels about the time of uncertainty. A counselor is a figure of authority and shares information that can make a patient feel confident. The messages that healthcare workers express voice can stick with the patient, whether or not it is supportive and compassionate.

Research Questions

RQ1: What memorable messages do BRCA positive individuals recall hearing from their loved ones?

RQ2: What memorable messages do BRCA positive individuals recall hearing from their healthcare workers?

RQ3: What memorable messages do BRCA positive individuals recall hearing from their coworkers and acquaintances?

Methods

This study focused on research that would give qualitative data. This was through a survey to answer the guiding research questions. This design collected quotes and

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messages that participants remembered when discussing BRCA positive test results. Having open ended questions in the survey allowed for qualitative data to be collected. The survey allowed for communicative moments (e.g., memorable messages) to be explained based on the questions criteria. This allowed the research to gain insight on lived experiences of BRCA positive patients. The approach used was able to capture many different situations and connections. Qualitative data was used to answer RQ1, RQ2 and RQ3.

Procedure

Data for this study were collected through questions via Qualtrics. The study was an initial pilot study for a larger study in the future that will explore compassionate communication for individuals who tested positive for BRCA gene mutations. The goal of the research is to help individuals communicate more compassionately with women who have tested positive for BRCA gene mutations. The survey had a total of seven questions including demographics and inquiries related to memorable messages. The first four items were demographics for the study and the final three are regarding memorable messages of BRCA positive interactions. The qualitative questions based on memorable messages were collected with the following prompt: “A memorable message is something that you remember an individual saying to you that has stuck with you and perhaps impacted the way that you think, feel, or act. The message can be positive or negative. It simply needs to be memorable.” The first being based on messages from a friend, romantic partner, or family member. The second based on memorable messages from a healthcare worker. The third on memorable messages from a coworker or

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acquaintance. Then followed by asking about a certain area of people. The completion time of the survey averaged to be two minutes and 38 seconds.

Sample

Data were composed of 123 responses with 114 individuals that are BRCA positive and qualified for the study. Participants were recruited through social networks (e.g., Facebook and Instagram) and their responses were anonymous. The participants were all women and the age ranged from 19 to 75 ($M = 42.11$, $SD = 11.42$). There was little variety in the ethnicity/racial identity of participants, 112 responses were collected consisting of 95.5% ($n = 107$) White/non-Hispanic, 1.8% ($n = 2$) Black/non-Hispanic, 1.8% ($n = 2$) Hispanic, and .9% ($n = 1$) Asian or Pacifica Islander. Each question regarding memorable messages recorded a different number of responses from the 114 that qualified for the study. The most frequently responded to survey item was about family, friends, or romantic partner (62.2%, $n = 71$); followed by healthcare workers (55.3%, $n = 63$); and then coworker and acquaintances (49.1%, $n = 56$).

Qualitative analysis

For the types of memorable messages to be examined, the author engaged in an open-ended coding process. The researcher read the data multiple times in order to be familiar with the data and then created individual codes to capture the themes of the data. Each question on memorable messages had varying themes for their responses. Once themes of memorable messages were identified for each question the researcher was able interpret the data collected and apply it the research questions.

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Verification

When analyzing themes memorable messages with family, friends, or romantic partners the four categories were shown in most messages by response 22. By this response there was four saturated themes: support, optimism, community, and discouragement. There are few responses that did not fit into any of the themes. These responses were meaningless or did not comment on the situation at all or they were not a message. Some responses were descriptions of the whole experience rather than a message. 5.6% ($n = 4$) of the responses did not fit into any category or have a common theme between them.

Four themes were found in memorable messages from healthcare workers. These categories were saturated by response 15. The four themes found were education, support, directness, or empowerment. Most responses fell under these four categories but 9.5% ($n = 6$) of the responses did not agree with any themes or have common ideas between them. These responses were the participant mentioning that they did not have any memorable messages or describing an emotion instead of reciting a message.

In the third section, memorable messages from coworkers or acquaintances were analyzed. There were five themes found: support, curiosity, apology, humor, and religion. The five saturated categories were developed by response 40. Few messages disagreed with these themes. 14.3% of the responses did not align with any theme. Most of these messages were “none” or “na,” participants did not remember anything or wrote that they did not tell any coworker or acquaintance.

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Results

To answer RQ1, RQ2, and RQ3 the thematic analysis of memorable messages in each item of the survey family, friend, or romantic partner ($n = 71$); healthcare workers ($n = 63$); and coworkers or acquaintances ($n = 56$). There were several themes revealed in each item related to memorable messages. The analysis of results was over three different items. There were themes within memorable messages from family, friends, or romantic partners; healthcare workers; and coworkers or acquaintances (shown in table 1). Some themes from each item overlapped, while others did not. A few themes were specific to the person that the message was coming from and may have been impacted because of this. Some messages also fit under two themes depending on how they were communicated.

Memorable message themes of family, friend, or romantic partner

The first question of the survey asked for memorable messages that a BRCA-positive individual received from a family member, friend, or romantic partner. For this item there was 71 response that led to four themes found: support, optimism, community, and discouragement (shown in table 1). Support was most prevalent in this collection of memorable messages. This theme was consistent in 30.9% ($n = 22$) of messages. The second most common memorable message was presented through optimism. This theme was seen in 22.5% ($n = 16$) of responses. Community was a common theme when coming from family. 19.7% ($n = 14$) of responses hinted at creating a community or having a sense of community. The smallest theme found in family, friend, or partner

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messages was discouragement. 19.7% ($n = 14$) of the responses were discouraging toward the diagnosis or participant.

Support

Family, friends, and romantic partners offered support to the BRCA positive participant. Messages that participants experienced were supportive with words of encouragement. These messages usually supporting the participants decisions or creating a safe space. Most supportive messages were encouraging for the participant. For example, participants remembered being told: “You are capable and brave” (46), “You got this!” (44), or “You are so strong and have the best positive attitude” (58). These are a few examples that showed their support through encouragement and kind words. The message is complimenting the participant. Other participants remember specifically being told that they are supported by their family members. One participant for example recalls: “I support whatever you want to do. It’s your body” (75). There were also supportive messages that attempted to normalize the BRCA mutation diagnosis. For example, participants remember: “It’s normal to feel all the thing” (122) or “This gene doesn’t change who you are” (43).

Optimism

Optimism is similar to support in the sense of creating a safe space and being encouraging. However, this focuses on the messages that were positive about the future and circumstances. These messages from family, friends, or romantic partners may be looking toward the next step and making it positive. This approach may be attempting to

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distract from all the obvious negatives that can come with a BRCA positive result. Many of the messages tried to focus on the knowledge and information that this diagnosis brings. There were five participants that remember: “Knowledge is power” as a means of optimism to show that this information is good. Another example a participant remembers is “What a miracle that we can find out and stop it before it’s cancer” (40). For most of these messages, it was putting an emphasis on the positives of finding the BRCA mutation. It also alluded to optimism toward future actions that may take place.

Community

A third theme that the research recognized was community. Many of these messages had the word “we” in them to show that it was a team effort. These messages wanted the participant to know that there was a community standing with them during this difficult time. These messages were similar to support because they were encouraging the participant, but they used a group aspect. Some participants recall messages from their husband, for example: “Honey, we will get through this.” (37), “This is a part of our life now and it will be okay... We will deal with it as it comes.” (49), or “We now know what to put our time, talents, and treasure into.” (6). The romantic partner in the mentioned participants lives were giving the participant a community by saying that they were facing the problem together. Community was also shown in messages to participants by making sure they knew that they were not alone. For example, “We will do whatever we need to, to help you stay healthy” (10) or “We will do this together” (68).

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Discouragement

Discouraging messages had negative connotations and looked at the BRCA positive result as a terrible situation. Messages that were discouraging varied from aggressive messages, comments that addressed the likelihood of the participant having cancer or devaluing the meaning of the positive result. A participant recalled the message “Don’t let those doctors cut on you!!” (20). Messages like this were aggressive toward the participant and forcing their ideas on the participant. A couple more messages participant remembers receiving are “Cancer doesn’t care how healthy you are. If it wants you – it’s coming for you” (39) or “You’re a ticking time bomb” (47). These messages were reminding the participant of their hard future. They were comments that made sure the participant knew how bad cancer was and how likely they are to get it. Some participants also recalled a message that belittled the diagnosis. Messages said were “You’re too young to have cancer.” (63) or “It’s not that big of a deal” (12).

Memorable message themes of healthcare workers

The second item of the survey asked for memorable messages from healthcare workers. The 63 responses created four themes: education, support, directness, and empowerment (shown in table 1). The most frequent theme was education. 31.7% ($n = 20$) of responses aligned with education. The second most prevalent theme was support. Participants had 27.0% ($n = 17$) of the responses fall under the theme of support. Following support was directness. These responses were 22.2% ($n = 14$) of the messages recalled by participants. Empowerment was the fourth theme found in the messages from healthcare workers. 17.5% ($n = 11$) of responses were empowering to the participant.

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Education

Educational messages had a piece of information or education with them. They consisted of statements, statistics, future decisions, and advice. Healthcare workers seemed to attempt to inform these participants. A way that healthcare workers were educating participants was by making them aware of options in the future. Memorable messages like “You have options” (22) or “There are options, and we can discuss anything you would like here is my cell phone number call anytime.” (10). Healthcare worker were showing that they cared by informing the patient and making sure they knew what was happening. An example of statistics that a participant remembered was “You have and 85% chance of having it [breast cancer] in you healthy breast if we don’t act now.” (17). The statistics are given to show what the chances are of the future. This education was to make a patient aware of what is to come. Many of the educational pieces mentioned what is going to need to happen next for preventative reasons. These educational messages were meant to aid participants in their future decisions. A few examples from participants are: “We need a hysterectomy and double mastectomy soon.” (40) or “You will have to have your ovaries removed” (65). The education and information on procedures was an attempt to make their patient look at what is to come.

Support

Support from healthcare workers can take on my different forms. They can be support towards a decisions or extra encouragement in times of fear. One participant recalled a message from her radiologist. The radiologist said to her “You are making a

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very wise decision.” (61). This support gave the participant a little extra encouragement and tried to make her feel better about the decision that was being made. Participants also remembered messages like: “This is your journey; you need to do what’s best for you.” (75) or “I am sorry you are having to go through this.” (30). These messages were encouraging and supportive coming from the healthcare workers. They were trying to show that they are there for their patient and console them through this difficult time. Another common message seen from a couple healthcare worker was “Knowledge is power” this was seen in family too.

Directness

Many messages from healthcare worker were direct. These messages were straightforward and to the point. Most of these did not leave room for a lot of emotion. They were clear and direct in the way that they were formed. Some participants remember being told their diagnosis in a direct way; for example, “Your test was positive. You can pick up your results the front desk.” (12). This type of message was straightforward and left little room for any other questions or concerns. It was very direct and to the point, this type of message can come off as insincere. Some examples that participants remember are as follows: “You have to remove everything that makes you a woman.” (36) or “It’s not if but when.” (64). These messages may not have the intent to be insincere or to the point, but they are set up to be short and clear. These direct messages may be similar to support and education based on the content. However, the way they are communicated is what makes them direct and straightforward.

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Empowerment

An empowering message will look similar to support and could fall under the same category. However, when a message was empowering the healthcare worker is giving authority to someone and encouraging confidence in the participant. Participants remember messages that gave them power and confidence. For example, “You have the power to decide” (27) or “It is ultimately your decision, we can only give you the data.” (45). These messages attempted to give the patient autonomy of their body and empower them by reminding them it is their choice. It also is a way of showing that they have control over their life. Other messages that showed empowerment were compliments aiming to be a confidence booster. One participant remembered “You are a warrior; warriors win!!” (69). This is an attempt for a healthcare worker to give the patient a sense that they are strong.

Memorable message themes of coworkers or acquaintances

The third group of messages was from coworkers or acquaintances. Of the 56 responses received, this item of the survey generated five themes: support, curiosity, apology, humor, and religion (shown in table 1). Support was most frequently found in messages from coworker or acquaintances. Messages with support were 42.8% ($n = 24$) of the responses. Another common theme found was curiosity. 16.1% ($n = 9$) of response were curious. The theme apology had the same number of responses as curiosity. 16.1% ($n = 9$) were apologetic and giving pity to the participant. Humor was the fourth theme found in these messages. It was not very common and made up 10.7% ($n = 6$) of

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responses. The least common theme found in messages was religion. Only 3.6% ($n = 2$) of the messages were religious.

Support

Support was mentioned in the previous two items too and has been a common theme in the whole study overall. Support was a way of showing care to the participant in the difficult time. Many of the messages attempted to offer something for support. A few examples from participants include: “We are here for you. You take whatever time you need.” (7), “If there’s anything you need I can help, you just let us know.” (25), or “you know what you have to do, and we are all behind you” (21). Each of these messages aimed to make the participant feel comfortable with what was happening. These responses were all from coworkers or bosses, and they each offered to help the person with work whenever it is needed. There was an attempt to offer help and comfort for the participant. Other forms of support were shown through compliments. Participants recalled: “You’re an inspiration.” (18) or “You are brave” (123). Messages were encouraging the patients and showing support by giving out compliments. A common message found from coworkers to multiple participants is “Knowledge is power.” This message was also seen with family and healthcare workers.

Curiosity

Coworker and acquaintances were curious about what BRCA was and wanted to learn from the participant. Many messages were asking questions. A few examples participants remember are “I’m sorry to hear, can you explain more about this gene?”

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(10), “What does that mean?” (29), or “What can I do to help?” (42). Many of these messages were asking what the gene was or how to help. They were wanting to learn and be aware of what was happening. Most of the messages that were curious were in the form of a question. However, there are a few that showed their curiosity through statements of their actions. A participant remembered a coworker saying “I didn’t know anything about BRCA before you telling me. I went home and did some research on the gene mutation, and I want you to know I’m in awe of you.” (34). These responses did research and educated themselves but made the participants aware that they were trying to understand. Most of the messages that are curious are attempting to show their care and support through wanting to learn more.

Apology

These messages did not say much more than sorry. Apologetic messages had pity for the situation and felt bad for the participant. This was an attempt to feel bad for the participant and show their condolences to the hard situation. A few examples participants remembered were “I’m so sorry. It must be tough.” (15) or “Oh my goodness, I am so sorry to hear that.” (64). Some of the messages offered their condolences and offered to help if needed. For example: “I’m sorry to hear that. If there’s anything you need. Just let me know” (55). These messages wanted to show that they were sorry for the circumstances by offering to their services.

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Humor

Humor was seen as both good and bad depending on the participants. Some participants mentioned that it was a good way to distract them from the circumstances. In contrast, some felt that the jokes were inappropriate and invasive. Examples of jokes that some participants appreciated were “Least you get a free boob job” (17) or jokes about tattooing something different on the new breasts instead of nipples (26). These jokes were taken as humorous and were good for the participant. However, some participants received similar jokes and it felt invasive. One participant recalled being asked and having comments made about reconstruction and felt that these were invasive. Humor can be taken as a stress relief to some but to others it may be uncomfortable.

Religion

Religion was a small category. However, this is a unique theme that brings religion into the message. These messages would try and show support and love by bringing up praying or God. This response could be beneficial to some participants but could be overstepping for others. A couple of examples participants remember are “I’m praying for you” (40) or “We love you and are praying for your best.” (50). These messages are attempting to show that they care and are thinking of the participant. They are acknowledging the hard circumstances and offering condolences through prayer.

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Table 1

Examples of quotes within each theme

<i>Item</i>	<i>Theme</i>	<i>Example(s)</i>
<i>Memorable messages from family, friends, or romantic partner</i>	Support	“You are capable and brave” (46) “I support whatever you want to do. It’s your body” (75)
	Optimism	“What a miracle that we can find out and stop it before it’s cancer” (40).
	Community	“This is a part of our life now and it will be okay... We will deal with it as it comes.” (49)
	Discouragement	“You’re a ticking time bomb” (47) “It’s not that big of a deal” (12)
<i>Memorable messages from healthcare worker</i>	Education	“You have options” (22) “You have an 85% chance of having it [breast cancer] in your healthy breast if we don’t act now.” (17)
	Support	“This is your journey; you need to do what’s best for you.” (75)
	Directness	“Your test was positive. You can pick up your results the front desk.” (12)
	Empowerment	“You are a warrior; warriors win!!” (69)
<i>Memorable messages from coworker or acquaintance</i>	Support	“We are here for you. You take whatever time you need.” (7) “You’re an inspiration.” (18)
	Curiosity	“I’m sorry to hear, can you explain more about this gene?” (10)
	Apology	“I’m so sorry. It must be tough.” (15)
	Humor	“Least you get a free boob job.” (17)
	Religion	“We love you and are praying for your best.” (50)

Note. Each item asked about in the survey is shown with their corresponding themes. The themes show an example(s) of memorable message(s) from a participant(s). Respondent number that correlates to quote is in parentheses

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Discussion

This study looked at messages or comments that have stayed with a person for an extended period of time known as memorable messages (Knapp et al., 1981). It specifically asked patients that have tested positive for the BRCA gene mutation to share their experiences. Participants were asked to respond to a survey regarding their positive diagnosis and the memorable messages they have received. The responses gave insight to different disclosures from friends, family, or romantic partners; healthcare workers; and coworkers or acquaintances. Each item gained many responses from anonymous people through social media. This study was able to look at varying examples of communication in different social groups, it analyzed how different relationship interact with an individual. In addition to this, the study provides more information on common themes of memorable messages for people going through a time of uncertainty. It works to provide new insight on communication behaviors and patterns between people that are disclosing sensitive information.

The BRCA gene mutation is a unique experience that many will not experience but it can create a difficult time in a person's life. These times of difficulty and uncertainty lead to people relying on loved ones and healthcare workers. The results led to new insight and common experiences between participants. Interactions with people surrounding a BRCA positive individual led to many common themes identified in memorable messages.

Memorable messages with family, friends, or romantic partners led to mainly positive interactions. Many messages toward BRCA-positive people fell under four categories: 1) support, 2) optimism, 3) community, and 4) discouragement. The least

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common theme was discouragement. Discouragement had a wide variety of messages and was a distinctly different theme than the others. Most family members, friends, and romantic partners were supportive and attempting to look on the positive side while making the individual feel safe. Overall, most memorable message that participants recalled were helpful and kind from these social groups.

The second social group studied was healthcare workers. BRCA-positive patients have many interactions with healthcare workers and of importance to this study with genetic counselors. These memorable messages had four different themes: 1) education, 2) support, 3) directness, and 4) empowerment. Many healthcare workers offered support while educating their patient on the circumstances and future steps. There were messages that were direct and to the point. These did not leave much room for emotional support and were very straightforward with the conversation. Direct messages had both negative and positive connotations.

Messages from coworkers and acquaintances was the final social group looked at. This group had a wide variety of themes when interacting with a BRCA-positive individual. There were five themes found: 1) support, 2) curiosity, 3) apology, 4) humor, and 5) religion. Most of the messages fell under support. However, others created distinct categories different from the healthcare workers and family, friends, and romantic partners. Messages with support were kind and attempted to help the participant. Curious and humorous messages had both negative and positive results. Some felt invasive and uncomfortable with these messages, while others enjoyed this response. Apology was a simple theme that did not have much variation. The least common theme was religion,

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with messages offering to pray. These responses also had the most that did not fit into any theme because participants did not coworkers or acquaintances about their diagnosis.

Each item in the survey gained meaningful insights on themes that participants experienced in memorable messages from the people surrounding them. These themes and commonalities lead to an in-depth analysis of interactions with BRCA-positive patients. Connections are made between memorable messages and the group from which they are received. The study indicates that varying relationships generate different responses during times of uncertainty. This can lead to numerous implications based on the survey results.

The memorable messages that BRCA-positive patients recall vary depending on where the message is coming from. When looking at memorable messages from family, friends, or a romantic partner the study saw support, optimism, community, and discouragement. Each group of messages from this social group was interesting to find. It was expected to have support and optimism. Community was not a theme that other research has displayed but it shows another way of having compassion toward the situation. Discouragement was an unexpected theme that arose. Findings suggest that when receiving messages from these people they will most likely be positive and supportive. The messages in these close relationships tend to use words of encouragement. These types of messages are beneficial for a patient. Kaufman et al. (2021) stresses the importance of positive and supportive memorable messages as a proper coping mechanism when facing challenges.

The participants that receive supportive and positive messages are more likely to deal with their diagnosis better. Hearing these messages can lead to the feeling of hope.

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The study showed that many husbands would try and create this positive environment by creating a community and making it a shared experience. Many of the messages came from romantic partners, showing that they play an essential role in a BRCA-positive person's life. This echoes what Fekete et al. (2007) finds. Partners are a major support system for patients that are going through BRCA testing. The messages from partners made the participant feel valued and heard, encouraging them to remember that message. This result was expected from partners and family.

Hopeful messages that are encouraging from friends, family, and romantic partners are the ones most commonly being remembered by participants. They are talking hope into their situation similar to what Merolla et al. (2017) discusses. These people have hard decisions to make and are met with many empathetic and compassionate memorable messages. Remembering these messages is a form of relief. It can take some pressure away and decrease suffering for a patient. This is why most memorable messages from family, friends, and romantic partners are positive. The patient is using their support system as a release of suffering, like Cameron et al. (2015) suggests in their research.

The communication and relationship between the participant and their family, friends, or romantic partner is essential to creating a safe environment. There needs to be effective communication to help the situation. It is expected that these relationships would be supportive and helpful to a patient with the BRCA mutation. The messages from these people that were received in the survey show that the communication in the relationship is important. There were many messages that created a comfortable environment and aided in the conversation about risks and future choices, supporting

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research conducted by Datta et al. (2017). Participants that did not have positive interactions would state their negative experience or put the message they recalled that was discouraging.

It was not expected to have many discouraging messages from family, friends, and romantic partners. It was a surprising result to see the number of messages that were negative. These messages were hurtful to the participant and have impacted them greatly. Since this type of message was recalled before a positive message it shows that the negative comment left an impact. The participant was talking to someone they love or value and hearing a negative comment from this person of importance created a negative memory over the positive ones. Prior work has not shown the way that discouraging messages from family, friends, and romantic partners may affect the patient. However, it is known that it is influencing them enough for it create a memorable message.

Similar to family, friends, and romantic partners healthcare workers play a large part in how a participant feels about their BRCA diagnosis. The most responses were shown with family, friends, and romantic partners showing that this is the largest group influencing BRCA-positive patients. However, the number of responses based on messages from healthcare workers was not too far behind. This shows that healthcare workers also play an important role in interactions with BRCA-positive patients. Based on the results from this study, it disagrees with Smith et al. (2009b) mentioning that healthcare workers have the largest influence on breast cancer patients.

Messages from healthcare workers fell under the themes of education, support, directness, and empowerment. Each of these themes were not surprising to find. BRCA gene testing is an important decision to make and face, so it is expected that educational

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messages would be seen the most frequently. This aligns with several previous pieces of research displaying that healthcare workers and patients have many educational interactions. Lerman et al, (1996), van der Giessen et al. (2021), and more have found that patients learn from genetic counselors, receiving proper education, to help aid in future decisions. Many of the education messages were educating patients on their risks and future treatments. It is expected that healthcare workers are educating their patients. Educational messages can feel very direct and technical, Leading to another common theme found with healthcare workers.

Explaining procedures and protocols can seem very straightforward and emotionless. This studies theme of directness is similar to research done by Werner-Lin (2008b). These messages and interactions are technical and do not leave much room for emotional support or discussion. This can leave the patient feeling lost, these types of memorable messages are not productive for creating a positive environment. A patient likely would feel frustrated with this interaction. These memorable messages go against research done by Puski et al. (2018) that say genetic counselors should have positive conversations with patients to create the feeling of reassurance, support, and validation. Direct messages failed this and showed that many patients did not feel comfortable. However, the supportive messages that were provided aligned with Puski et al. (2018). There was little compassion and empathy found in these messages.

Support as a theme was not a surprise when analyzing results. This theme was second largest, after education, showing that it was more prominently remembered than directness. Healthcare workers supported their patients by encouraging their decisions and using uplifting words. These experiences can create a positive reaction and aid in the

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time of uncertainty, supporting Jeffery (2016). The messages that support a patients decision help shape their behaviors. Messages of empowerment also do this. They created a place of comfort and encouragement by complimenting and uplifting the patient. This creates a hopeful atmosphere that patients look forward to being a part of.

The final item the study focused on was memorable messages from coworkers and acquaintances. The five themes that were found were: 1) support, 2) curiosity, 3) apology, 4) humor, and 5) religion. Support was the most common theme, and this was expected. Many of the messages that were supportive were similar to the messages from family and friends. However, coworkers could offer support in different way than family, friends, or healthcare workers could. The supportive messages usually included offering to help cover shifts or parts of work. This could be expected from coworkers. It is a way of showing support through acts of service. They were not offering emotional support like other people. It also can show that relationships between people and the coworkers are not as close as other parts of support systems. There is not the same level of trust established so there is less emotional support offered.

This can also explain why apology is not a surprising theme. An apology is simple and does not tend to leave room for details. This could be expected from acquaintances and coworkers. There is not a close relationship created with these people, so not much more takes place then an apology to show sympathy.

Humor and curiosity were unexpected themes. Both of these themes are seen as partially invasive. Jokes made about physical appearance of future treatments were taken badly by some participants, while others appreciated the humor. The participants that felt it was inappropriate felt that it invaded their privacy and belittled their diagnosis. These

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messages are negative and have influenced the participant. However, the participants that enjoyed the humor felt that it relieved some stress and made the stressful situation a little more fun. These two reactions to humor can be based on how close the participant may be with their coworkers, the work environment, or the context of the message.

There is a similar situation with curiosity. Some participants felt a violation of their privacy when asked questions, but others appreciated that people were trying to understand. The connotation of curiosity is based on the context and setup of the message. When a message was asking about certain procedures or noticeable changes the curiosity felt unwelcomed, However, when a message was worded to show that they were wanting a better understanding of the circumstances it was received better. This also may depend on the relationship between the participant and person asking.

Memorable messages from coworkers and acquaintances received the least number of responses. Several responses received said “none” or “na” to show that the participant did not talk to any coworkers or acquaintances. This says something about people’s relationship with this social network. These relationships may not be close or trustworthy, so there is not any disclosure of sensitive information. People may not feel comfortable talking to these people because there is not as high of expectations that they will be supportive and compassionate. Family, friends, and romantic partners are expected to be kind and supportive, so participants are more inclined to share information. Also, healthcare workers are expected to respond well to the situation and hold the information private, so a patient is comfortable talking to them. However, there is little expectations for coworkers and acquaintances. The lack of expectations may lead to why their memorable messages can be seen as invasive or inappropriate.

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In the results of all three items one common sentence came through. “Knowledge is power,” this message was seen in responses from each item. This sentence is simple but interesting when analyzing. Each relationship, no matter the different expectations, stressed the importance of knowledge. This message shows that having education on the situation and the circumstances can be meaningful. BRCA-positive patients should feel powerful and feel a sense of control having the knowledge of the mutation. They are able to be educated on it and be aware of what may come in the future. Like mentioned in the literature review, being educated and aware of the risk involved with genetic testing can be beneficial to patients.

Support as a common theme for each item proves the importance of support from the people surrounding a person. If there is a strong support system the situation can be easier to navigate. In addition, it shows that no matter the expectations of a relationship times of uncertainty bring out the support in people. There is a shared understanding that the situation is difficult and leads to several more tough decisions in the. BRCA-positive patients receive support and recall many supportive messages. There are more compassionate, supportive, and positive messages than others. Memorable messages are likely to be remembered when they are beneficial to the receiver. The message is influential and comes from a person of importance. There were few messages remembered with negative connotations, showing they were impacting these people less. Examining three different networks of people, allowed similarities and differences to be found intragroup and intergroups. Each group of people played an influential role in the participants life and decisions.

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Theoretical and practical implications

This study expands on the work of memorable messages and is able to give more insight on the importance of memorable messages. It aims to add to the theoretical implications of memorable messages in health communication. Past studies using memorable messages have found common themes when looking at them in healthcare settings. A few themes have been based on compassionate characteristics (Willer, 2014) like empathy, patient centered care, and hope to see how they affect actions and behaviors. Other themes were recognized around influence on action (Smith et al. 2009b). Both these types of memorable messages in healthcare enrich the study of memorable messages in healthcare and enable people to see common characteristics in influential messages in health communication. This study can add to this with the many different themes that were found. This study allowed researchers to see the varying levels of support from different groups and analyze how it can affect a BRCA-positive patient. Knowledge of memorable messages guided in exposing additional themes and characteristics of influential health communication. Deciding what messages are most memorable in different interactions is shown in this study.

In addition, this study brings forth practical implications for family, friends, coworkers, and genetic counselors. Family members and friends can be aware of the influence that their messages and comments have on BRCA-positive patients. Increasing the amount of support, compassion, and optimism in messages can create a safe environment and allow for proper emotional support. In addition being an effective communicator and strong support system allows for the fostering of hope and generate

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positive experiences. Also, there are expectations as a family member or friend to be kind rather than discouraging. Coworkers should look into the relationship they have and take this into consideration while communicating. Be cautious of personal space and what may or may not be acceptable to mention when communicating with a BRCA-positive patient. It is also good to understand that each situation is different and facing it with support and compassion is the most productive and memorable if done properly. If a message is invasive or inappropriate it will be remembered over the positive messages. As a coworker or acquaintance, be cognizant of the context and situation. Genetic counselors and healthcare workers would benefit by bringing in more compassion when communicating with their patient. Messages that were compassionate and kind were remembered and more influential. Incorporating this would allow for your patient to be more open and impacted by information being shared at that time.

Limitations and future directions

This study adds to the theory of memorable messages and current work done on health communication with BRCA-positive individual, but it is important to recognize the limitations. The survey brought in a wide variety of participants, but the date of their diagnosis was not specified. There was not a question asking for the date of diagnosis or relating to the timeline of the patients experience. In addition, how much time has passed since receiving the message was not looked into. The results may have been impacted by the duration of time since the memorable messages and since the BRCA diagnosis.

Another limitation to note is that not all participants answered each question. The survey received many responses, but some only answered the demographic questions,

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affecting the percentage of results and themes. Some participants gave more than one memorable message for the question, while others described an experience or emotion rather than providing a message. This could have impacted which response was used for differing themes. Majority of the responses received did not include how the participant felt about the message. It would be beneficial to add this to properly place the message into the theme. Without this knowledge it is possible the messages may be interpreted differently than the participant experienced it. This may have impacted the results of the themes and implications.

A final limitation to note is how long the survey was out for and the medium through which it was sent. The survey was open to responses for a little under a month and this could have affected the amount and type of responses. There was also not a wide range of groups, majority of the participants were White/non-Hispanic. Regarding the medium of the survey, it was spread through social media like Facebook and Instagram. These platforms were beneficial to quickly spread the survey but can lack in the variety of participants. The survey was sent out to one support group on Facebook but could have benefitted from sending it to a greater number of support groups and people. The number of results may have influenced the themes and could have been adjusted with a larger sample.

In the future, it would be beneficial to gather the emotions that people felt when receiving a particular message. Collecting this data may be done best through an interview process, rather than a survey. This would allow for greater implications to take place. Future research may also want to look into the relationships with coworkers specifically. This groups of people created an interesting number of themes. Insight on

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these relationships and social expectations could enhance the understanding of the message. Focusing more on how the relationships between the BRCA-positive individual and sender may the impact of the message would allow for significant conclusions to be made. What remains to be researched is how these compassionate and supportive messages are affected by the relationships had and how these varying communication behaviors affect future actions and treatment.

Conclusion

This research focused on memorable messages offered to BRCA-positive individuals from their loved ones, healthcare workers, and coworkers. After a thorough qualitative analysis of the experiences in BRCA-positive disclosures, numerous findings were studied. Differing support systems brought up different themes that have affected the experience of the BRCA-positive person. The themes from loved ones are support, optimism, community, and discouragement. Majority of these messages offer compassion, empathy, and support. Aligning with the social expectations that are put on loved ones in times of uncertainty and difficulty. Messages from healthcare workers offered education, support, directness, and empowerment. These aligned with past ideas about healthcare workers. They were supportive but lacked compassion. Coworkers and acquaintances brought interesting themes to the surface: support, curiosity, apology, humor, and religion. Support was expected from these groups of people, but the other themes came as a surprise. Health communication plays into risk communication regarding sensitive topics. It is important to look at how types of memorable messages are influencing people struggling with a BRCA-positive diagnosis. This allows for

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appropriate messages to be sent out in hopes to aid individuals struggling with the BRCA mutation.

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