Investigating Initial Disclosures and Reactions to Unexpected, Positive HPV Diagnosis

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Initial disclosures of health conditions are critical communication moments. Existing research focuses on disclosers; integrating confidants into studies of initial disclosures is needed. Guided by the disclosure decision-making model (DD-MM; Greene, 2009), this study examined what diagnosed persons and confidants may say when faced with unexpected test results and unexpected disclosures, respectively. Participants (N = 151) recorded an audiovisual message for another person, after imagining that they or the other person had just received unexpected, positive HPV test results. The qualitative analysis revealed four themes: (1) impression management and social distance, (2) invisible symptoms and advice regarding future disclosures, (3) expressing and acknowledging emotional reactions, and (4) misunderstandings and lacking knowledge about HPV. These findings suggested that DD-MM may be a relevant framework for understanding not only when disclosers share, but what disclosers and confidants say in early conversations about new diagnoses. While disclosers’ and confidants’ messages showed marked similarities, important differences appeared. For example, confidants focused on assuaging disclosers’ fear about the consequences, whereas disclosers expressed distress related to their uncertainty about the prognosis of an HPV infection and how to prepare for next
steps. The discussion highlighted implications for the DD-MM, HPV disclosures, and future interventions.

Keywords: Confidants; Decision-Making; Disclosure; HPV; Sexually Transmitted Infection; Stigma

Unexpected, positive test results may evoke different reactions in patients and their loved ones: uncertainty regarding the condition and how to address it, fear or worry about the severity of the condition, curiosity about how one contracted it, and concerns about its social consequences. These cognitions and affective reactions may be uncomfortable to experience, and consequently may encourage people to talk with others in order to manage them to more comfortable levels. Disclosure, then, is a critical communication moment, which is gaining much theoretical attention, such as the disclosure decision-making model (DD-MM; Greene, 2009). DD-MM outlines factors that predict whether diagnosed persons disclose their diagnosis to other people. Existing work on initial disclosures of health information often focuses on diagnosed persons (e.g., those receiving test results), but increasing attention has been paid to diagnosed persons’ confidants (Smith & Hipper, 2010) and how confidants’ cognitions and affective reactions shaped their own communication with diagnosed persons. Integrating confidants into our understanding of initial disclosures is a critical need.

Even with this increased attention to disclosers and disclosures, to date, studies rarely evaluate spoken communication in these initial moments to assess what those facing unexpected test results or those facing an unexpected disclosure say. To address this gap, this study explored the possibility that DD-MM factors may be themes in what diagnosed persons say when they make initial disclosures to their confidants, and how confidants initially talk to disclosers. This study examined what participants recorded in an audiovisual message for another person, after imagining that they or the other person had just received the unexpected news that they are infected with human papillomavirus (HPV). A qualitative analysis allowed the researchers to identify emergent themes in these initial reactions, to compare and contrast themes based on the participants’ imagined role in the disclosure dyad, and to discuss them in context of DD-MM (Greene, 2009).

Initial Conversations about Positive HPV Test Results

HPV is a relevant topic for college students. Recent reports of national prevalence for women (Hariri et al., 2011) report that the highest rates appeared in young women: 32.9% of 14–19-year-old females and 53.8% of 20–24-year-old females tested positive for an HPV infection. Fewer studies of men exist; an existing study shows that 51% of heterosexually active, men, aged 19–40 without a prior history of genital warts tested positive for HPV (Nielson et al., 2007). HPV DNA testing has been advocated, which would increase the likelihood that women and men would learn their HPV status (Kahn et al., 2007). Most diagnosed persons disclose to at least one person. Previous
studies revealed that people were most likely to disclose their HPV diagnosis to their current sexual partner, followed by their close friend, family member, and roommate (McCaffery, Waller, Nazroo, & Wardle, 2006; Perrin et al., 2006).

Theoretical Perspectives on Health Disclosures

Communication scholars have considered the motivations for health disclosures. DD-MM (Greene, 2009) provides an integrated perspective on the motivations for disclosure in interpersonal contexts. Recent survey experiments show support for the model’s ability to predict the reported breadth, depth, and frequency of disclosure (e.g., Checton & Green, 2012; Greene et al., 2012). DD-MM is considered a model for disclosure in interpersonal settings (vs. public announcements) with existing, close others (vs. health practitioners).

In DD-MM, diagnosed persons are argued to assess three factors when deciding whether to disclose their health information to another person. DD-MM entails three assessments related to (a) the health condition, (b) receivers, and (c) disclosure efficacy. Initially, persons assess the health condition based on five characteristics: “stigma, preparation, prognosis, symptoms, and relevance to others” (Greene, 2009, p. 229). Stigma refers to expectations of society’s negative reaction to the health condition. Preparation refers to how much the person may have expected the diagnosis. This study focused on an unexpected diagnosis or low preparation and in these cases, Greene (2009) stated that disclosers may express more emotions, as they vent and seek emotional or instrumental support. Prognosis refers to the qualities of the health condition (e.g., acute or chronic) and treatment options, and is likely to arouse uncertainty. Symptoms refer to physical signs of the health condition due to disease or treatment; the appearance of physical signs may unintentionally disclose a health condition. Relevance to others refers to how the confidant’s health may be implicated by the disclosure; for example, the confidant may need to be tested as well for a contagious condition.

Greene (2009) argued that some of these factors may be more salient or prominent in this decision depending on the health condition. For example, for sexually transmitted infections, diagnosed persons may consider the stigma and relevance for others first and foremost (Greene, 2009). HPV has been referred to by college students and other sources as a sexually transmitted infection (Sandfort & Pleasant, 2009; Smith & Parrott, 2012), although other forms of transmission have been documented, such as mouth-to-mouth and nonsexual, skin-to-skin contact (e.g., Gillison, 2008; Gillison, Chaturvedi, & Lowy, 2008; Ogilvie et al., 2009). Existing research shows that HPV infections are stigmatized, and people with HPV infections experience stigma-related psychological distress (e.g., Marhefka et al., 2012). Thus, stigmatization and concerns for others may be particularly salient for an unexpected HPV diagnosis.

Additionally, a cancer-related prognosis may be salient because college students are aware of the association between HPV and cervical cancer (Sandfort & Pleasant, 2009; Smith & Parrott, 2012). Uncertainty around positive-HPV test results is high (Kosenko, Hurley, & Harvey, 2012): such as its meaning and separation from other
diseases, such as herpes, its progression, and the source of infection. In contrast, HPV has few visible symptoms that are likely to be unintentionally noticed, which may lower symptoms’ salience. For unexpected HPV diagnosis, then, stigma, relevance to others, and prognosis are likely to be salient, whereas symptoms are not.

After assessing the health diagnosis, people assess the potential receiver based on the quality of their relationship with the confidant (e.g., intimacy/closeness) and the confidant’s likely response to the disclosure (e.g., support, rejection; Greene, 2009). With greater closeness to the confidant and anticipating a positive response, disclosure is more likely to occur. If, after assessment of the health diagnosis and potential confidant, the risks associated with disclosure are less than the need to disclose, then disclosers move to a final assessment of their disclosure efficacy. Disclosure efficacy is defined as the confidence and ability to disclose a specific piece of health information to a specific receiver.

DD-MM (Greene, 2009), then, includes eight variables, which are expected to predict whether diagnosed persons disclose their diagnosis to other people. This study explored the possibility that these eight variables were also themes in what diagnosed persons say when they make initial disclosures to their confidants. In the context of HPV, for example, disclosers may talk about their relationship to the confidant and the possibility of cancer. They may also highlight their own uncertainty in how they contracted HPV, in order to disassociate themselves from a taboo topic (sexual transmission) or stigmas, depending on their relationship with the confidant. In order to explore these initial conversation patterns, the following research question was posed:

**RQ1**: What do college students say to a close loved one, while imagining that they have received an unexpected positive test result for HPV?

**Confidants’ Reactions**

DD-MM’s eight variables may also help us to understand observed patterns in confidants’ initial responses to disclosers’ communication. One theory supporting this idea is communication privacy management (CPM; Petronio, 2002; Petronio, Sargent, Andea, Reganis, & Cichocki, 2004). One assumption in CPM is that when a person discloses his/her condition to a confidant, the two become co-owners of this information. Co-owners share in the knowledge of the discloser’s diagnosis, regulation of this knowledge, and its consequences. Under this rationale, confidants’ decision-making models include many elements of and show similarities to disclosers’ models (i.e., DD-MM). For example, when considering the stigmas, confidants are likely to consider and to advise taking action to avoid stigmatization in a similar fashion to disclosers (Smith & Hipper, 2010).

As confidants generate their initial responses, then, they may consider HPV-related stigmas (e.g., sexual-transmission), cancer prognosis, preparing for next steps, symptoms, relevance for others (e.g., disclosure to current sexual partners or health care professionals), their relationship with the diagnosed person, the diagnosed person’s reactions to the news, and their own efficacy to have this discussion.
The themes in confidants’ recordings, then, may be the same as those in the disclosers’ recordings (e.g., “no one else has to know”—discloser and confidant) or complementary (e.g., “I feel alone”—discloser; “you’re not alone”—confidant). In order to explore these initial reactions, the following research question was posed:

\[ RQ2: \text{What do college students say when they imagine that someone they care about has received an unexpected positive test result for HPV?} \]

**Method**

**Participants**

The sample consists of mid-Atlantic, US students \( (N=151, 54\% \text{ females}) \) enrolled in multiple sections of a communication course required of multiple majors. Participants ranged in age from 18 to 26 \( (M=20.01, SD=1.14) \). Students self-identified as White \((87\%)\), Hispanic \((5\%)\), African American \((3\%)\), Asian/ Pacific Islander \((2\%)\), or multiracial \((1\%)\), or were unidentified \((2\%)\). Almost half of the students \((48\%)\) had received at least one of the HPV vaccines \((70 \text{ women, 5 men})\). Fewer \((27\%)\) had been tested for HPV \((37 \text{ women, 5 men})\) with just a few testing positive \((5 \text{ women})\). Chi-square tests and \( t \) tests were used to assess whether participants in the two conditions differed in their demographic characteristics; none were statistically significant.

**Procedures**

In this study, participants were instructed to imagine either that they had received positive HPV test results (referred to as disclosers) or that someone they cared about had received positive HPV test results (referred to as confidants). Afterwards, they were directed to record a message for the other person who wanted to hear from them, but was currently unavailable. Participants recorded their messages facing a camera on a computer. The advantage of this procedure was its ability to capture the anticipated conversational patterns for these two roles in health disclosure conversations. Phone and e-mail messages are ubiquitous forms of such asynchronous conversations. With greater audio-video capabilities, video messages are increasing as well (Smith, Rainie, & Zickuhr, 2011). In addition to real-life relevance, these recordings allowed the researchers to explore each participant’s attempt at an initial disclosure or an initial reaction without interruption.

Participants arrived at the communication laboratory and met a research assistant (blind to the study’s objectives) who showed them to the computer to complete the online survey items. When the survey was complete, participants found the research assistant next door for help with setting up the video recording. The research assistant left the room while the participant completed the survey and the video-recording. The survey asked participants for demographic information and their experiences with HPV testing and vaccination. Participants were all instructed to share what they knew about HPV in an open-ended question. These initial knowledge responses appear in another study (Smith & Parrott, 2012).
Next, participants were asked to imagine one of two scenarios (randomization to condition occurred via coin flip). Half of the participants \((N = 71)\) were assigned to the discloser condition, and instructed to imagine that they had just received the news that they had tested positive for HPV. In the scenario description, they had consented to the test when the doctor suggested it as a part of a routine checkup (participants were not symptomatic), but had not expected it to be positive. These scenarios, then, related to two characteristics of the DD-MM: symptom invisibility and lack of preparation. After reading this story, disclosers were asked to write down the name of the person they would talk to first about these test results, and their relationship to this identified confidant. Afterwards, disclosers were asked to imagine that this identified confidant wants to talk with them but cannot (unavailable), so they are making a recording. The other participants \((N = 80)\) were assigned to the confidant condition, and instructed to imagine that a close friend or family member just received the news that he/she tested positive for HPV. The close friend/family member had gone to the doctor for a routine visit and consented to the test, but did not expect it to be positive. After reading this story, confidants were asked to write down the first name of the person they were imaging when they read the story, and their relationship to this person. They were then asked to imagine that this person wanted to talk with the participant about this news, but was unavailable. Participants were asked to record a message for their close friend/loved one.

**Analysis Procedures**

All of the audiovisual participant responses were transcribed verbatim by one of the authors who also coded all of the response videos. Themes were allowed to emerge organically. Using constant comparative method (Strauss & Corbin, 1990), codes were collapsed to identify core themes (Mills, Bonner, & Francis, 2006). After engaging in open coding (i.e., identifying, naming, and categorizing different phenomena present in the data) to identify emergent themes, the author who transcribed the data then conducted axial coding (relating categories to each other, such as causal relationships), and the other author conducted selective coding (focusing on particular categories as core ideas, and relating other categories to it). Both authors discussed emergent patterns in the data, and worked to refine and collapse patterns through several meetings. Saturation was achieved after two discussions of emergent patterns in the data. The author who transcribed and conducted the initial open and axial coding was blind to the study’s purpose, in order to avoid a priori expectations for themes. Disagreements about the findings were resolved through discussion. Themes were interpreted and then compared to DD-MM during selective coding.

**Results and Discussion**

**Descriptive Statistics**

Participants in both the discloser and confidant conditions were asked to identify the first name of the other person they imagined in this conversation, and to categorize
their relationships with the individuals they chose. (Participants could select more than one category, thus the percentages may sum to greater than 100%). Participants categorized their loved ones as best friends (36%), parents (25%), close friends (25%), significant others (11%), current sexual partners (10%), siblings (10%), roommates (9%), classmates (5%), health care professionals (1%), Categorization did not differ between conditions, except for siblings and parents. More confidants were thinking about siblings (8.5% of the total) than disclosers (1.5%), \( \chi^2(1) = 7.30, p < .01, r = .22 \) and more disclosers imagined speaking to their parents (18% of total) in comparison to confidants, \( \chi^2(1) = 13.96, p < .0001, r = -.30 \). Chi-squared tests showed no differences by gender.

**Communication in Response to a Diagnosis**

Recordings, on average, were 35.99 seconds long. The average response was 40.41 seconds for confidants, and 30.83 seconds for disclosers. The average response length was 39.22 seconds for females and 32.22 seconds for males. Emergent major themes revealed patterns of communication by confidants and disclosers, and included impression management and social distance, invisible symptoms and advice regarding future disclosures, expressing and acknowledging emotional reactions, and misunderstandings and lacking knowledge about HPV. Each of these themes is discussed below in greater detail, with specific examples; particular participants are identified with a random number to keep their identities confidential. The findings are presented, as possible, in reference to the stages of DD-MM: information assessment, receiver assessment, and disclosure efficacy.

**Misunderstanding and Lack of Knowledge about HPV**

Disclosers and confidants both expressed misunderstandings about HPV and limited information about it. One confidant was unsure of whether HPV or HIV is more severe (2158M). Contrary to current scientific knowledge that vaccines were designed to address particular HPV strains and are unlikely to provide cross-protection to other strains (e.g., Brown et al., 2009), two disclosers believed that vaccinations rendered the vaccinated immune to HPV (2063F, 2079F). Discloser 2043F asked, “If I received HPV shots, does that guarantee that I will not contract [sic] the HPV?” One discloser (2019M) and one confidant (2076F) did not understand the impact of HPV on males; either they did not believe that it impacted males, or did not understand how it would affect males. There was also misinformation about HPV’s association with cancer. Confidant 2050F said,

> I think this disease that you have been diagnosed with is something... that you can’t prevent because it’s a type of cancer, I believe it’s cervical cancer. So, it’s inevitable for you to get it... so you shouldn’t even be worried what people have to say, because it’s not like you went out of your way, and were unprotected in having sex or in using needles when getting a shot, or having blood taken.
A few confidants referenced their lack of knowledge in their responses to a potential confidant. Confidant 2064 M admitted a dearth of knowledge about HPV and stated, “I’ll be honest with you, I don’t really know much about HPV, so I don’t know how much help I could be for you.” Confidant 2040 M viewed general unawareness of HPV as a benefit,

I don’t know anything about HPV but I don’t think that anyone else really know[s] that much about it either so I don’t think anyone’s opinion would change that much if they knew if you have it, or didn’t have it.

This confidant believed that ambiguity about HPV may buffer some potential social stigma.

Disclosers and confidants differed in their intersections with this theme. Disclosers openly expressed greater unawareness and understanding of HPV than confidants, which may reflect greater salience of prognosis for disclosers over confidants. Both disclosers and confidants expressed inaccurate information about HPV as a condition, which resonates with existing research showing general confusion about HPV (Friedman & Shepeard, 2007; Licht et al., 2010).

Expressing and Acknowledging Emotional Reactions

Confidants and disclosers spoke about the emotional impact of receiving a positive HPV diagnosis. Discloser 2049F confided, “I’m really scared and I think you can help me with this.” Confidant 2028F provided comfort by saying, “I’m really sorry that you have to find out about this, and I know it might be kind of devastating to find out that you got HPV.” This confidant acknowledged the emotional reaction that might occur as a result of this diagnosis.

Discloser 2011F revealed, “I just found out that I was diagnosed with HPV, and I’m kind of scared because I don’t know what to expect.” Another discloser (2023F) speculated about the potential long-term consequences of this diagnosis, and stated, “I know that it can cause cancer, so I’m really worried about it, and I just wanted to ask you a few questions . . . because I’m really worried.” These examples highlight how uncertainty about what is next and the long-term consequences of this diagnosis generated negative feelings among disclosers.

Expressing surprise at the diagnosis, Discloser 2059F said, “I was not expecting this. It was hard to hear that this would happen.” Discloser 2041F expressed uncertainty about how she contracted HPV: “I don’t know how I got HPV and I’m kind of scared, so could you come to the doctor with me to check to see if we could find out some more research?” Discloser 2019 M also expressed uncertainty about how he, as a man, could contract HPV, “Mom, I think I have HPV. I’m not really sure how I got it because I think it only affects women.” This discloser’s lack of knowledge about HPV gave him a sense of uncertainty and ambiguity about the condition.

Confidant 2012F acknowledged the unexpectedness of the diagnosis, saying, “I know this was a surprise . . . even though you didn’t really want it to happen, no one is going to think any less of you; we’re all here for you to help you get through
this.” This confidant pledged ongoing emotional support, and reassured the discloser that their relationships would remain intact. Discloser 2077F confided emotional distress as a result of uncertainty and said, “I don’t really know how it happened, but I’m kind of freaking out because I don’t know what to do.” Confidant 2070F gave some emotional support and practical advice, stating, “Don’t worry, it’s just an STD, you can get it treated just go to a doctor, that way you are not at risk for more health problems.” This confidant gave practical steps to minimize the impact of the positive diagnosis. Disclosers also tried to reassure confidants about their prognosis. Discloser 2089F said, “I know that HPV is a cervical cancer,” and discloser 2006 M said, “Mom, I have cancer. It’s ok. I guess I’ll just live the best way I can. It’s ok.”

The communication discussed in this theme highlights the relationships between cognitive reactions such as uncertainty, and affective ones, such as fear. In this theme, confidants’ communication differed from disclosers’ in that confidants focused on assuaging disclosers’ fear about the consequences, whereas disclosers expressed distress related to their uncertainty about the prognosis of an HPV infection and how to prepare for next steps. These differences provided important insights into how some DD-MM (Greene, 2009) variables may be more salient and trigger different emotions for diagnosed persons in comparison to their supporters. The amount of emotional material supported Greene’s (2009) prediction that in situations where people are not prepared for the news (e.g., unexpected diagnoses), emotions may be strongly and frequently present in the discussion. These findings highlight how both disclosers and confidants may bring up and attempt to reassure each others’ emotions.

Impression Management and Social Distance

One theme in the initial reactions focused on possible social consequences of the diagnosis specifically how others in general and the confidant particularly may see the discloser and may socially distance themselves from him or her. This theme, then, can be seen as relating to both information (possible stigma) and anticipated responses (e.g., worry about rejection versus social support). The interpersonal concern was brought up by both disclosers and confidants: Disclosers asked if anything would change, whereas confidants reassured that nothing would change in their relationship. For example, discloser 2095 asked, “Do you think of me differently as person, and how do you think this [diagnosis] will affect our friendship?” The social consequences of disclosing a positive HPV diagnosis, then, may create worries in terms of its potential to mar one’s identity, to draw social rejection from others in general, and also to create a specific rift in their personal relationship. One response from confidants was to reaffirm positive impressions, and to separate the diagnosis from disclosures’ identities. Confidant 2101 said, “You are a great person, and you have a lot of things going for you; don’t let this change you.” Confidant 2088 echoed the recommendation “don’t change,” and assured their friend, “Basically, this could happen to anyone . . . HPV is a problem, but it doesn’t change you as a person.” By suggesting that anyone could have received this diagnosis, Confidant 2088 separates the diagnosis from the discloser’s actions and character.
Even for those who felt assured about stability in their specific relationship, reactions by others were raised. Discloser 2053 said, “I know that this [diagnosis] won’t change anything in our friendship, but I was wondering how it’s going to affect what I do in my life, and relationships with boys and other friends, in the future?” This discloser maintained the relationship with the confidant, while exploring other social consequences. Confidant 2109 said, “We’re still gonna love you, you’re still you, I still love you. You’re still the smartest person I know, you’ll still do great in school . . . . Nothing changes our perception of you, we still love you completely.” This confidant reaffirmed impressions of the discloser’s intelligence and social status, as well as the strength and stability of their own, interpersonal connection. Many of these statements sought to maintain social relationships, and also encouraged disclosers to preserve a positive self-identity, and discouraged having the positive diagnosis “change who they are.”

In this theme, many messages were complementary. For example, disclosers asked about identity and relationship changes, and confidants provided reassurance that their impressions of the disclosure and their relationship had not changed. The responses from both disclosers and confidants suggest a connection between impression management and social relationships. As noted in other studies, female college students assumed that promiscuous people contract HPV (e.g., Hopfer & Clippard, 2011); contracting HPV may challenge college students’ sense of self. The responses showed simultaneous efforts to manage individual identity and preserve social relationships, suggesting that these two concepts interact. In the discussion of DD-MM, Greene (2009) discussed how relationship quality may override stigma’s tendency to dampen disclosure. Disclosers who anticipate positive responses from close loved ones may disclose stigmatizing information. The results in this study showed that the relational concerns may infuse the disclosure and initial reactions by attempting to get and give reassurance that the diagnosed person is not tainted by the health condition and their interpersonal relationship remains strong. Tensions between social rejection and disclosure have been reported by women living with HPV (Kosenko, Hurley, & Harvey, 2012).

Invisible Symptoms and Advice Regarding Future Disclosures

Disclosers asked for advice about and confidants gave unsolicited advice about future disclosures. Confidants emphasized that the invisibility of a positive HPV diagnosis gives disclosers a choice about whether to continue sharing this information with others. Confidants asserted that disclosers have control over this information because HPV is not readily visible in everyday interactions. This theme provided support for DD-MM’s emphasis that symptoms play a role in disclosure decisions.

Seeking advice on whom to tell about the diagnosis, discloser 2009 asked, “[Can you give me any advice] on how I would manage or tell people about getting the disease?” Discloser 2029 M expressed uncertainty about with whom to confide, and asked, “Who do you think I should go to talk about this? I’m not really sure what to do right now.” This discloser hoped to elicit some guidance about with whom to share his diagnosis. Confidant 2076 advised,
If you are careful and smart about your decisions, you won’t have to feel uncomfortable or feel that you have to tell a bunch of people. You don’t have to tell anyone that you don’t want to. Except if you are sleeping with someone, obviously that is wrong not to tell them that, and I know you know that.

Confidant 2076 emphasized the discloser’s control over the information as well as a moral obligation to share it with sexual partners. Obligations to report to current or future sexual partners have appeared in previous qualitative studies of women living with HPV (Kosenko, Hurley, & Harvey, 2012). Confidant 2074 also advised on controlling the information, stating, “You don’t have to tell anyone, or advertise to the world that you have this.” Another confidant (2077) emphasized the “invisibility” of HPV, and the importance of disclosing positive status to a sexual partner, and said, “No one can tell you have it. You don’t have to tell anyone you have it unless you’re, you know, intimate with them, then you are kind of obligated to tell them.” Discloser 2017 reflected on who should know about the diagnosis and said, “Obviously [the diagnosis is] something that people who I am close to should know about, especially people that are close to me that I would be in relationships with.” Once again, the most relevant other for the diagnosed is likely to be potential sexual partners. Highlighting the invisibility of HPV and control over future disclosures, Confidant 2143 said,

Most people won’t even know you have HPV. It’s not like there is a dog smelling your crotch that’s just gonna go around telling your secret. The only people that are going to know are the people you tell.

Confidant 2143 used imagery to reassure the discloser that they have complete control over information about the diagnosis.

The intertwined discussion of invisible symptoms and control over future disclosures shows the strong relationship between these ideas, providing support for DD-MM (Greene, 2009). Confidants emphasized that the potential invisibility of HPV ensures that diagnosed persons can control who knows that information. Confidants frequently reminded disclosers of this control, perhaps to reassure the disclosers that they will not face any negative social consequences as a result of this diagnosis if they did not choose to reveal the information. These findings contribute to Greene’s (2009) DD-MM, because both disclosers and confidants addressed informational control and emphasized the imperceptibility of HPV. Further, confidants reminded disclosers about the information’s relevance for sexual partners; indeed, sexual partners were often referenced as the only party who has a right to know about the diagnosis. These findings provide insight into DD-MM, but also suggest a potential point of contact between theories of disclosure and those of social support. We analyzed initial disclosures and responses: in a longer study, one might ask when the DD-MM model becomes irrelevant.

Limitations

The discloser-participants gave shorter responses than the confidants, perhaps because they approached the task as if they were leaving a voice mail, while the
confidants simulated a one-sided conversation. This inquiry may have benefitted from the probes that occur naturally in conversation. On the other hand, as noted by an anonymous reviewer, the difference in length may suggest topic avoidance on the part of the disclosers. In addition, the study used a hypothetical scenario, which may be taken less seriously or be subject to greater social desirability (Caughlin et al., 2009). That said, none of the participants reported that making the audiovisual recordings was unnatural; in contrast, many had made and sent recordings to their loved ones. In many of the responses, it was easy to imagine the individual confidants and disclosers in this study as two sides to one conversation, suggesting a level of realism. Further, their answers were not consistently positive or tame (e.g., the crotch-smelling quote by Confidant 2143). Observing video-recordings contributed to a holistic and nuanced understanding of how communication manifests as a result of a positive HPV diagnosis.

Replication, of course, should be tested in future studies. The themes noted in this study, framed well by DD-MM, resonate with those found in a qualitative study of women living with HPV (Kosenko, Hurley, & Harvey, 2012): uncertainty about the diagnosis, its prognosis and disclosure issues related to possible stigmatization, relevance for others (e.g., future partners or children). Observing actual initial disclosures from diagnosed persons to their confidants will benefit from considering not only relational roles of confidants, but also relationship quality to further test DD-MM. Natural conversations among those receiving a real diagnosis are ideal, not just to investigate the conversational content, but also who is present for initial disclosures. The people imagined in these scenarios may be participants’ ideal conversational partner, who may not be present in real encounters. For example, many more disclosers imagined talking with their parents, than being their parent’s confidant. This asymmetry may be due to the health condition (HPV), which is associated with young adults, but it may also represent anticipated or preferred intrafamily dynamics. These findings, then, provided their own important unique contributions to our understanding of disclosure dynamics for unexpected diagnoses.

**Implications for Those Testing Positive for HPV and Future Research**

Limited materials have been created for those testing positive for HPV (Kosenko, Hurley, & Harvey, 2012). These findings provided critical insights into a relevant theory for framing such materials, and the potential need for different materials targeting diagnosed persons and their confidants. Four themes were identified in video-recordings of college students imagining that they were disclosing an unexpected positive HPV diagnosis to a close loved one or that they were the loved one hearing this disclosure. These four themes—(1) impression management and social distance, (2) invisible symptoms and advice regarding future disclosures, (3) expressing and acknowledging emotional reactions, and (4) misunderstandings and lacking knowledge about HPV—resonated strongly with Greene’s (2009) model of health disclosure decision-making (i.e., DD-MM). These findings suggest that DD-MM may be
a relevant framework for understanding not only when disclosers share, but what disclosers and confidants say in early conversations about new diagnoses. Analyzing video-recordings of both disclosers and confidants allowed us to observe that some variables in DD-MM may be more relevant for disclosers than for confidants, and may trigger different reactions based on one’s role in the conversation. The method of observation may also perform as an intervention to develop communication efficacy (Afifi & Weiner, 2004). Privately more than one of the participants shared with the researchers after the study that they felt more confident to be involved in such a discussion after practicing. These findings align with Pennebaker’s work (e.g., 1997) on the benefits of emotional expression through writing or speaking.

Conclusion

Greene and colleagues (2012), when studying DD-MM with surveys, stated that actual responses by confidants are critically involved in understanding health disclosure decisions. This study’s findings showed how confidants addressed many of the variables predicted to shape disclosers’ disclosure decisions (Greene, 2009). Further, the study showed that DD-MM factors are not just psychological; they manifest in conversational content of both disclosers and confidants. Both disclosers and confidants expressed issues related to distance: attempts to keep the discloser’s identity separate from the diagnosis and worries about social distancing by others based on the diagnosis. Both disclosers and confidants raised the topic of future disclosures. Confidants emphasized how the invisibility of HPV’s symptoms provided disclosers an opportunity to control their future disclosures and to make careful choices. Both disclosers and confidants expressed a lack of awareness about HPV; disclosers particularly expressed distress related to their uncertainty about their prognosis and how to prepare for next steps. Finally, this analysis revealed that there is still widespread misunderstanding about HPV (Kosenko, Hurley, & Harvey, 2012). The participants’ responses highlight how misinformation about HPV may be shared or reinforced in interpersonal interactions, providing possible avenues for designing materials to support those receiving a positive HPV test and their loved ones through their initial conversations. The findings also highlight how misinformation may be unintentionally provided by confidants as a means to make diagnosed persons feel better: communicating that it is not one’s fault may confuse issues of risk, transmission, and responsibility, and should be studied.

References


