<u>An integrative review of the influences on decision making of young people about Human</u> <u>Papillomavirus Vaccine</u>

Sisson, H., & Wilkinson, Y.

<u>Abstract</u>

The HPV vaccine is a key intervention in the prevention of HPV infection and associated cancers. This review emphasises the importance of understanding what influences decision-making about this vaccine. Guided by the work of Whittemore and Knafl, and Pluye and Hong, we identified 25 studies, from which four prominent themes emerged: fear and risk, pain, parental involvement and involvement of others. Fear of cervical cancer was a strong motivation to receive the vaccine, and the extent of parental involvement also had an impact on decision-making. Recommendations to receive the vaccine by healthcare providers was also an important influence. School nurses are fundamental to the promotion and delivery of the HPV vaccine and should stress the significant role that it plays in the prevention of cancer. Additionally, school nurses should ensure that discussions about HPV infection and vaccine includes parents where appropriate, and should distinctly recommend vaccination to those eligible.

This is the accepted version of an article published as Sisson, H. & Wilkinson, Y., An integrative review of the influences on decision making of young people about Human Papillomavirus Vaccine, Journal of school nursing v35(1) pp. 39-50. Copyright © 2018 The authors. DOI: [10.1177/1059840518805816].

Keywords: adolescents, decision-making, Human Papillomavirus vaccine, integrative review, school nursing, young people.

Background

The Human Papillomavirus (HPV) is a viral infection transmitted by direct contact with an infected individual (Public Health England (PHE), 2014). Over 100 different types of HPV are known and categorised as low or high risk; low risk types are responsible for genital warts, with types 6 and 11 causing the majority, and HPV types 16 and 18 are common high risk types, associated with the development of cervical and other HPV related cancers (American Academy of Pediatrics (AAP), 2017). The prevalence of HPV is considerable in sexually active individuals; it is estimated that most people will become infected during their lifetime (WHO, 2016).

Currently three HPV vaccines are licensed; one offers protection against two virus types (16, 18), while a second offers immunity against four (6, 11, 16, 18) (WHO, 2016). A third vaccine providing protection against an additional five types (31, 33, 45, 52, 58) recently became available (Petrosky, et al., 2015). These vaccines were introduced in many middle to high income countries in the mid-2000s, but with the support of the Global Alliance for Vaccines and Immunization (GAVI), coverage is extending to low-income countries (GAVI, 2018). By the end of 2014, HPV vaccination was available in 64 countries (Bruni et al., 2016). As HPV types 16 and 18 are attributed to 70% of cervical cancer cases (WHO, 2016), vaccination programmes originally targeted females, and the WHO recommends vaccination for girls aged 9-13 years, citing this strategy as the most cost effective public health measure against cervical cancer (WHO, 2016). However, males are now able to access HPV vaccination, with the US and Australia being among countries routinely offering this to boys aged 11-12 and 12-13 years respectively (Australian Government, 2017; Centers for Disease Control and Prevention, 2016). The target population for this vaccine identifies school nurses as pivotal in its implementation

and success. Studies have explored and found that school nurse education and attitude towards the HPV vaccine is key to answering parents and young people's questions about the vaccination (Grandahl, Larsson, Tydén, & Stenhammar, 2017; Rhodes, Visker, Cox, Forsyth & Woolman, 2017; Rosen, Ashwood & Richardson, 2015). This vaccine requires multiple doses, offered as a two or three dose schedule, with an uptake recommendation of 80% (WHO, 2017). Vaccination against the Human Papillomavirus is a safe and effective method of preventing the initial infection and associated cancers (WHO, 2016). Uptake statistics show differences globally, (Bruni et al., 2016). US data indicate that approximately 60% of the eligible population received an initial dose and less than 40% received all required doses (Walling, Benzoni, Dornfeld, Bhandari, Sisk, Garbutt, & Colditz, 2016). Conversely, UK uptake is at 88% for all required doses among females (PHE, 2015) where school nurses have been key in the delivery and promotion of this vaccination being at the interface with health and education (Bartlett and Peterson, 2011); less developed countries demonstrate significantly lower rates although this inextricably related to coverage (Bruni et al., 2016).

As parental consent may be required, studies have explored parental attitudes towards the vaccine. Ogunbajo, Hansen, North, Okoloko and Niccolai (2016) found parents considered the HPV vaccine similar to other routine adolescent vaccines, reporting positive attitudes towards the vaccine's ability to prevent cancer. Similarly, although more generally, Askelson, Campo, Lowe, Smith, Dennis and Andsager (2010) found that positive attitudes toward the HPV vaccine increased mothers' intentions to vaccinate. Conversely, Kinder (2016) investigated reasons for HPV vaccine deferral in the US and cited reasons including the vaccine's perceived novelty and need for further research as major parental concerns. Parental consent for HPV vaccination has been reported by parents as implicit approval for sexual activity (Scarinci, Harces-Palacio & Partridge, 2007; Schuler, Reiter, Smith & Brewer, 2011), but this finding has also been disputed (Askelson et al., 2010; Marchand, Glenn & Bastani, 2013). Other influences

on vaccine uptake have been reported by the vaccine eligible population, as vaccine access, and opinions of clinicians, parents and teachers (Batista Ferrer, Trotter, Hickman, & Audrey, 2014). Factors associated with uptake include having public insurance, which was found to be associated with lower initiation and course completion rates in the US (Dempsey, Cohn, Dalton & Ruffin, 2011; Tiro, Tsui, Bauer, Yanada, Kobrin, & Breen, 2012). Lower initiation rates are also associated with non-white and African American individuals (Chao, Velicer, Slezak & Jacobsen, 2010; Dempsey et al., 2011), as are lower income and educational attainment (Chao, Velicer, Slezak, & Jacobsen, 2010; Tiro et al., 2012). Whilst these studies provide useful demographics, understanding what influences decision-making in young people themselves is crucial for those working at the forefront of vaccine delivery, so that efforts to optimise uptake are focused effectively.

In 2006, the first HPV vaccines were licenced, with Australia, the US and Canada being the first to offer routine vaccination by 2007 (Markowitz, Tsu, Deeks, Cubie, Wang, Vicari, & Brotherton, 2012). A decade on from this and with rates still indicating a significant variation in uptake, it is fitting to develop an understanding of what influences young people's decision-making by drawing together and synthesising published findings; the review was guided by the question: what influences young people's decision-making around HPV vaccination?

Coughlan and Cronin (2017) cite that a theoretical framework provides a backdrop to a study, and the health belief model (HBM) originated by Hochbaum (as cited in Steckler, McLeroy & Holtzman, 2010), was seen as an obvious framework to contextualise the review's findings. This model is frequently used to explore health related decision-making and identifies four beliefs: that one is personally susceptible to a negative event, that the event is serious, that the advocated preventative measure is effective and will reduce the threat of the negative event, and that the measure will not incur a heavy personal cost. Two elements of cues to action and health motivation were subsequently added which Goodman-Brown and Gottwald (2008) describe as influences on health behaviour. We undertook an integrative literature review to explore what influences young people when deciding whether or not to receive the vaccine

Method

The methodology by Whittemore and Knafl (2005) was used to guide the review, but acknowledging that reviews using studies of mixed designs have a valuable contribution to make in understanding complex public health interventions, the work of Pluye and Hong (2014) regarding mixed studies reviews also informed the review's design. To increase transparency in the reporting of the review synthesis, elements of the PRISMA reporting standards (Moher, Liberati, Tetzlaff, Altman & The PRISMA Group, 2009) for quantitative synthesis and the ENTREQ statement for qualitative synthesis (Tong, Flemming, McInnes, Oliver & Craig, 2012) have been drawn on. The search was undertaken by both researchers, which clearly defined the search terms, databases searched, supplementary search strategies and inclusion and exclusion criteria (Pluye & Hong, 2014; Whittemore & Knafl, 2005). Using the keywords and Boolean operators cited in Table 1, the databases MEDLINE, CINAHL, PsycINFO and Education Research Complete were searched.

The initial search undertaken in April 2016 identified 45 studies, and an additional 17 papers were identified after reviewing the studies' reference lists. The search was repeated in March 2017 and a further two papers were screened; one was excluded, not focussing on the decision-making of young people. After the removal of one duplicate, 62 abstracts were screened by both reviewers using defined inclusion and exclusion criteria (Table 2). Eight records were excluded by reading the abstracts and the remaining 54 were assessed by reading the full text versions, where a further 29 records were excluded. The PRSIMA flow diagram (Moher et al., 2009) illustrates the search results (Figure 1); searching was undertaken by both reviewers. Twenty-five studies were included in the review and a summary is presented in Table 3,

consisting of 14 quantitative, eight qualitative and three mixed methods designs undertaken in the US, UK, Japan, Greece, Sweden, Denmark, Brazil, China (Hong Kong) and Australia between 2006 and 2016.

The ENTREQ and PRISMA statements prompt reviewers to assess study quality, referred to as data evaluation by Whittemore and Knafl (2005). Given the mix of study designs included in the review, quality assessment was undertaken using two appraisal frameworks; one for qualitative (Ryan, Coughlan & Cronin, 2007) and one for quantitative approaches (Coughlan, Cronin & Ryan, 2007). Elements of both frameworks were applied to the studies using mixed methods. The appraisal frameworks were developed by the same authors, allowing for a consistent approach whilst acknowledging the different methodologies. Both reviewers conducted the quality appraisal (Table S1); there was variation in the methodological quality of the studies, however they were all considered to be of sufficient quality for the findings to add to the body of knowledge.

Adhering to the PRISMA and ENTREQ standards, the process of data abstraction prompted the reviewers to develop a framework to depict the studies' key methodological features (Table S2). Both reviewers were then able to confirm that all studies met the criteria for inclusion.

Whittemore and Knafl (2005) describe the importance of a clear data analysis strategy. This review adopted a convergent qualitative synthesis, described by Pluye and Hong (2014) as combining the results of qualitative, quantitative and mixed methods studies and transforming into qualitative findings, the most common of which is qualitative thematic synthesis. This involved each reviewer independently considering the studies' findings, and similar results were grouped into themes. Then, both reviewers discussed the themes identified, before reaching an agreement regarding relevance and appropriateness. Findings were then re-examined to verify their alignment to themes. Having two researchers undertake the analysis

encouraged iteration, and facilitated discussions before reaching consensus; Pluye and Hong (2014) advocate iteration and discussion to promote rigour in thematic synthesis.

Results

The synthesis generated four themes: fear and risk, pain, parental involvement and the influence of others.

Fear and risk

Fear concerning vaccine safety was a guiding factor in eight of the studies (Bernard, Cooper Robbins, McCaffery, Scott & Skinner, 2011; Hodge, Itty, Cardoza & Samuel-Nakamura, 2011; Liddon, Hood & Leichliter, 2012; Mathur, Mathur & Reichling, 2010; Moreira, de Oliveira, Silva Neves, Costa, Karic, & Costa Filho, 2006; Oscarsson, Hannerfors & Tyden, 2012; Rosenbloom & Killian, 2014; Wakimizu, Nishigaki, Fujioka, Maehara, Kuroki, Saito & Uduki, 2015). Participants expressed concern regarding side-effects, which had a negative impact on uptake and intention. Rosenbloom and Killian (2014) and Wakimizu et al. (2015) reported uncertainty involving the longer term undesirable effects of vaccination, with participants in one study citing the newness of the vaccine as a contributing factor (Wakimizu et al., 2015). Bernard et al. (2011) also found participants were concerned over vaccine content. In addition to concern about vaccine safety, Donadiki et al. (2014) and Williams, Forster, Marlow and Waller (2011) reported participants were uncertain of its efficacy, with a further study citing that participants were anxious about the length of vaccine efficacy (Kwan, Chan, Yip, Cheung, Young, Lee, & Ngam, 2008). Conversely, Bennett, Buchanan and Adams (2012) and Bynum, Brandt, Sharpe, Williams and Kerr (2011) reported that the HPV vaccine was perceived as beneficial, which had a positive influence on vaccination uptake and intention.

Some participants expressed fear of the diseases the vaccine protected against, having a positive impact on uptake and intention. Wakimizu et al. (2015), Oscarsson et al. (2012) and

Cooper Robbins, Brotherton, McCaffery and Skinner (2010) reported fear of cervical cancer as a vaccination motivator. Prevention of cervical cancer was also a motivation cited by Marchand, Glenn and Bastani (2012). Additionally, Moreira et al. (2006) found that fear of cervical cancer influenced the decision-making process; however, this study questioned Brazilian females about their willingness to receive the vaccine prior to its introduction into the national programme. Cooper Robbins et al. (2010) reported that knowledge of an individual who had received a cervical cancer diagnosis or a history of an abnormal smear, positively influenced participants' decision to be vaccinated. Such experiences are cues to action cited in the HBM and the notion of motivation triggered by fear of cancer is also apparent. Conversely, Vanderpool, Van Meter Dressler, Stradtman and Crosby (2015) explored fatalistic beliefs in women aged 18-26 and reported the 'lack of control' over cancer as a dissuading factor in HPV vaccine series completion.

Three studies attributed vaccine refusal to perceived low risk of HPV infection (Getrich, Broidy, Kleymann, Helitzer, Kong, & Sussman, 2014; Kwan et al., 2008; Liddon et al., 2012), whilst Hodge et al. (2011) reported that participants did perceive themselves at risk and that this was a vaccination motivation. Hodge et al. (2011) also questioned males, who perceived themselves significantly less at risk of HPV (p = 0.008). The concept of anticipatory regret was examined; Christy, Winger, Raffanello, Halpern, Danoff-Burg, and Mosher (2016) reported males (n= 149, aged 18-24) were more likely to regret refusing vaccination and subsequently developing HPV when compared with the females studied, and this notion of anticipatory regret was associated with intention to receive the vaccine. Similarly, Oscarsson et al. (2012) described how the women in their study (n=17, aged 17-26) speculated about feelings of regret and guilt if they refused the vaccine but later contracted HPV, and Nan (2012) reported that loss framed messages were a persuasive factor in decision-making. Increased risk of HPV was also identified as a motivating factor by Bennett et al. (2012) and Bynum et al. (2011); although

expressed as either perceived susceptibility to HPV (Bennett et al., 2012) or perceived severity of HPV (Bynum et al., 2011). A survey administered to 406 female students aged 18-26 did not find an association between risk perception and vaccine uptake (Licht, Murphy, Hyland, Fix, Hawk, & Mahoney, 2010), and a further qualitative study interviewing 10 girls aged 17-18, reported their uncertainty of the need to receive the vaccine in terms of the perceived risk of HPV (Williams et al., 2011). Although not conveyed as 'risk perception', Rosenthal, Weiss, Zimet, Good and Vichnin (2011) found participants who had received the vaccine did so because they valued its importance, although how this was expressed is unclear.

The theme of fear and risk is fundamental to the HBM in terms of personal susceptibility, disease seriousness and risk associated with vaccination. Vaccine safety fears influenced participants' decision-making leading to non-vaccination. Conversely, vaccination was more likely where fear of HPV or cervical cancer was reported. Participants who perceived themselves at risk of HPV also expressed greater intention to be vaccinated.

Pain

This theme focussed on the anticipated and actual experience of vaccination related pain, and was identified in six studies, (Bernard et al., 2011; Cooper Robbins et al., 2010; Getrich et al. 2014; Gold, Naleway & Riedlinger, 2013; Hughes, Jones, Feemster & Fiks, 2011; Oscarsson et al., 2012; Wakimizu et al., 2015).

Wakimizu et al. (2015) found an association between pain and amount of vaccinations (three intramuscular injections), with one participant reporting severe pain, causing fear of subsequent vaccinations. Oscarsson et al. (2012) only alluded to injection pain as one disadvantage to vaccination, this did not appear to have a significant impact on vaccine uptake or completion. Similarly this was identified by Getrich et al. (2014) whose participants acknowledged pain, but did not identify as a dissuading factor. Gold et al. (2013) reported 78% of participants

experienced pain at the first dose, however this did not equate to non-completion of the schedule. Hughes et al. (2011) reported similar findings, with those reporting concerns about pain (n=5, ages 11-18) still receiving the vaccination. Bernard et al. (2011) and Gold et al. (2013) described pain as the most frequent concern, where pain was increased with HPV vaccine compared to other vaccinations. This appeared to be influenced by misinformation, and was a common observation amongst vaccinated and non-vaccinated participants. Interestingly, those who developed bruising or swelling (not explicitly linked with pain) after the first vaccination were significantly less likely to complete the schedule (Gold et al., 2013).

Actual pain or fear of pain had little or no effect on initiation and completion of the HPV schedule, and other physical symptoms such as bruising and swelling, were more influential on decision-making. This is rooted in the belief cited in the HBM which weighs up the cost and benefits of the recommended health promotion intervention.

Parental involvement

Wakimizu et al. (2015) reported that girls in their study (aged 10-19 years) discussed vaccination thoughts and knowledge with their parents. This did not always influence their decisions either way, but was a method of assessing their own thoughts. Sometimes, following such discussions, parental decisions took priority, although this was more notable for participants who were 'more reliant' on their parents (age unspecified). Hughes et al. (2011) studied 20 adolescent, mother, clinician triads where adolescents considered themselves as passive in the decision-making process; it should be noted that although they were aged from 12 to 16, half of them (n=10) were either 11-12 years old. Similarly, Cooper Robbins et al. (2010) found that younger participants were happy for their parents to make the decision; the study comprised of girls aged 12 to 16 years old. Although mutual decision-making was reported, some participants were unhappy for their parents to decide, and where disagreement

occurred, parental decisions often took priority. Refusal was not exclusive to HPV vaccination but tended to reflect parental beliefs regarding all vaccines, which were then transferred to the adolescents. Participants were younger in two further studies; Mathur et al. (2010) found that girls (aged 14-18 years) regarded their parents as the most important source of information about HPV and HPV vaccination. Likewise, although not ranked in importance, Gotvall, Larsson, Hoglan and Tyden (2009) reported that males and females (aged 14-19 years) also cited their parents as a source of information. Combined, Bynum et al. (2011), Marchand et al. (2012) and Oscarsson et al. (2012) studied older females (aged 17-26 years) who still valued the involvement of their parents in the decision-making process. Two of the studies expressed this in terms of maternal recommendation or approval, which impacted positively on uptake (Bynum et al., 2011; Marchand et al., 2012). The ages of the participants in the study by Oscarsson et al. (2012) ranged from 17-26 years, where it was reported that mothers were active in the decision-making process via inclusion in discussions, and an additional motivation was identified as the mother offering to pay for the vaccine.

The HBM proposes that cues to action are internal or external, and parental involvement had a compelling association with external cues influencing decision-making. Whilst parents were observed as passive participants in decision-making in some studies, in others they had more of a direct impact on decisions, in some cases overriding the adolescents' decision. Whilst parents of younger participants appeared more active in decision-making, older participants also valued parents' contributions, demonstrating that parents are significant external cues to action affected to some extent by the age of the young person concerned.

Influence of Others

Wakimizu et al. (2015) reported that participants received information on cervical cancer and the HPV vaccination from experts, parents and peers. In relation to their peers, this focussed on their experience and vaccination status; participants who had friends who had been vaccinated spoke of peer pressure. Oscarsson et al. (2012) and Williams et al. (2011) identified that peers who had been vaccinated seemed to normalise it and were seen as a motivating factor. However Bernard et al. (2011) found a negative consequence of peer support with a lack of accurate knowledge about the vaccine leading to an increase in fear which was exacerbated by misinformation about side effects; this study also interviewed nurses who perceived a lack of accurate information as playing a role in the girls' response to vaccination.

Wakimizu et al. (2015) reported participants received knowledge through school briefings, conversations with experts and primary information tools including posters, leaflets and television advertisements. Gottvall et al. (2009) and Oscarrson et al. (2012) also found that participants received information from several sources including the school, media and mailing and youth clinics. Mortensen (2010) found most participants heard about vaccination through a media campaign, with none receiving information from the general practitioner. Those vaccinated had discussed the vaccination with other people more frequently than those who refused, with older participants initiating discussion with their general practitioner, thus detailing again the difference between passive and active participation in decision-making. Interestingly participants in the study by Mathur et al. (2010) did not rate the media or mailing as influential however they did rate parents, clinicians and their own research as important, a finding supported by Bynum et al. (2011) who identified familial approval, friends' and doctors' recommendations the strongest predictors of vaccine uptake. Bennett et al. (2012) discuss unspecified 'important people', but clinicians, family and social networks are included.

Hughes et al. (2011) reported that clinicians used two distinct strategies for presenting the vaccine to families: either routinely like other vaccinations with no additional information, or framing it as optional, highlighting the risks and benefits. Where parents expressed hesitancy, clinicians were uncertain about engaging them in a discussion, perceiving the HPV vaccine to

be less important than others. This study highlighted the passive role played by adolescents, also evident in the study by Getrich et al. (2014). This indifference was magnified in an area where the population was exposed to more health disparities, whilst other participants demonstrated a more active role with the clinician, with their decision-making also involving discussions with peers and family (Getrich et al. 2014).

Recommendation by a clinician is identified by Rosenthal et al. (2011) and Marchand et al. (2012) as one of the most common motives for vaccine uptake. Rosenthal *et al.* (2011) found 98% of vaccinated women had both discussed the vaccination and received a recommendation from their clinician, 69.9% of those not vaccinated had not discussed it with their clinician, or if it had been discussed they had not received a recommendation. Marchand et al. (2012) identified similar results, out of 45 participants who initiated vaccination, 37 of these identified a clinician's recommendation as the most influential reason.

The influence of others on vaccine uptake is important, with clinician recommendations the most significant. Peer influence is associated with vaccine normalisation, and educational campaigns, media and the school remain important cues to action, however the impact they have specifically on uptake is difficult to quantify. In addition to being profoundly associated with external cues to action, these findings also align to the overarching notion of the HBM that individuals scrutinise information when decision-making.

Discussion

The first theme of fear and risk concerned the vaccine itself and the diseases against which it offers protection. Vaccine related fear was expressed in association with its novelty by Wakimizu et al. (2015), but the HPV vaccine was not introduced in Japan until 2010-2011, which is later than other studies in this review, perhaps suggesting that familiarity and subsequent confidence in the vaccine increases with sustained use. Vaccine fear was also

reported in relation to potential side effects, but this is not a phenomenon exclusive to the HPV vaccine as previous studies have also cited this as a factor influencing decision-making for other vaccinations (Mills, Jada, Ross & Wilson, 2005; Zangger Eby, 2017). Also pertaining to the novelty of the HPV vaccine was the approach used to promote it. Hughes et al. (2011) described that a paternalistic approach where the HPV vaccine was discussed making it a standard part of care like other vaccines increased uptake. Although only highlighted among some participants, it does suggest that communication strategies are influential on vaccination decision-making, a notion that has been more recently reported (Ames, Glenton & Lewin, 2017). School nurses are able to provide accurate information about the vaccine and HPV to young people and their parents/guardians and in many areas already have an established professional relationship with the young person and their parents/guardians (Rosen et al., 2015).

Fear of cervical cancer was reported as a motivating factor to receive the vaccine in several of the studies, indicating that vaccine promotion strategies which stress cancer prevention could be influential in increasing uptake. Whilst participants expressed fear of cervical cancer, the concept of risk was only examined in relation to the risk of HPV infection among participants questioned, where a positive correlation between perceived risk of infection and vaccine uptake or intention was reported. Additionally, participants perceiving themselves at an increased risk of HPV infection were older than those who perceived themselves as low risk. This could be explained if it is assumed that the older participants across the studies are more likely to be sexually active, and suggests that campaigns which highlight the future risk of HPV infection are especially important in younger vaccine candidates.

Although considered individually, relationships exist between the themes. It is acknowledged that fear had associations with pain; however, it was decided to discuss these independently for two reasons. Firstly, the concept of pain was a distinct factor in six studies indicating its significance in decision-making. Furthermore, HPV vaccination is a multi-dose schedule and experiences of pain post-vaccination have previously been cited as influential in course completion of other vaccines in children (Taddio, Chambers, Halperin, Ipp, Lockett, Rieder, & Shah, 2009). However, this is not substantiated in this review, and this finding concurs with a more recent review by Gallagher et al. (2016) who reported no association between pain and non-completion of the HPV vaccine series. However, contrary to the findings of this review, Gallagher et al. (2016) did not report an association between swelling and bruising and vaccine completion. Nonetheless, this review has highlighted pain as a consideration in the decisionmaking process, making it an issue clinicians should remain aware of.

The degree of parental involvement was largely dependent on the age of the child, with parents of younger children playing a more active role in vaccination decisions. This signifies the strong influence of parents, and such vicarious decision-making is often unavoidable, emphasising the importance of directing vaccination information towards both young people and their parents. Informed consent remains a fundamental tenet in health care but it can be a contentious issue if disagreement occurs between child and parent (Griffith & Tengnah, 2012; Wright, 2011). Children and young people have become increasingly involved in decisions regarding their health care and it is vital that vaccination providers understand the rights of the child and the parents in these circumstances (WHO, 2014). However, such situations are rarely straightforward and providers need to ensure that they are vaccinating within a defined legal framework relevant to national or local settings.

This review found that healthcare provider recommendations to receive the HPV vaccine were instrumental in increasing uptake, a finding which has previously been reported in reviews by Gamble, Klosky, Parra and Randolph (2010) and Batista Ferrer et al. (2014). Similarly, McIntyre, Zecevic and Diachun (2014) found clinician recommendation for the influenza vaccine, a major facilitator of uptake in adults. Parents and young people can readily access the school nurse; they are viewed as trusted professionals and are able to provide accurate

information and advice (Rosen et al., 2015). The role of vaccine provider, whoever it might be, is significant in influencing decision-making in young people and parents, and direct recommendations to receive the HPV vaccine should be viewed as a crucial external cue to action.

Strengths and limitations

A methodological strength of this review is the systematic and transparent approach used to identify the relevant studies, enhanced by the use of the PRISMA (Moher et al., 2009) and ENTREQ (Tong et al., 2012) statements. The searching, inclusion and analysis of relevant studies was also undertaken by both reviewers, facilitating an iterative approach, which contributed to the trustworthiness of the review. The findings of the review itself present a contemporary embodiment of the literature on the topic from a global perspective. It is also acknowledged that the review has some limitations, which are likely to impact on the external validity of the findings. Firstly, the young people in the studies reviewed were mostly female, with males being hugely under represented. Therefore, with the changes in HPV vaccination programmes globally moving towards the inclusion of males, the limitations of the findings should be recognised. Additionally, the age range of participants in the studies spanned from 10 to 26 years and although this is realised in the analysis and discussion, the difficulty of drawing comprehensive conclusions as a result is accepted. We did not include the term 'child*' in our search, and given that the HPV vaccine may be offered to individuals from 9 years old, it is possible that some relevant studies may have been overlooked. A final limitation concerns the different countries where the studies were undertaken. None of the studies were located in low-income countries and the majority (n=15) were undertaken in the United States. With the exception of the US, the remainder were located in countries offering some form of universal health coverage (Rodin & de Ferranti, 2012). This may have an impact on decision-making in general across all sections of the population and could also limit the global application of the

findings where a variety of policies and practices regarding HPV vaccination are in place; this is particularly relevant in less developed countries where vaccine coverage is low, yet the incidence of cervical cancer remains high (Bruni et al., 2016).

Implications for school nursing practice, research and education

This review has identified three central influences on decision-making in adolescents and young people: their desire to avoid cervical cancer, their parents, and clinician recommendations, and school nurses have a key role to play in this. Health promotion activities and vaccination information should stress the role HPV vaccination has in the prevention of cervical and other HPV related cancers. There is also a need for school nurses to involve adolescents and parents as much as possible in the decision-making process and to develop processes locally which can facilitate joint discussions where the need arises. Being at the interface between health and education they have access to the target population and their parents/guardians; they are able to deliver factual information and answer and respond to questions and concerns to enable an informed choice to be made. Furthermore, school nurses engaging with both adolescents and their parents should absolutely recommend vaccination. This requires being up to date with any associated training so that accurate information can be delivered with competence and confidence; clearly, such recommendations should also be made within the context of informed choice. Male participants in this review were vastly underrepresented and in view of the extension of the vaccination programme to include adolescent boys, it is suggested that further research which specifically investigates decision-making in males is undertaken.

Conclusion

Vaccination remains the most effective form of prevention against HPV infection and this review has explored what influences young peoples' decision-making. Whilst there is some

scepticism around the HPV vaccine, fear of cervical cancer is a substantial motivation to receive the vaccine; the vaccine's ability to prevent cancer must be stressed. Decision-making discussions with young people should appropriately involve parents as this review has found that they are pivotal influences in this process. Finally, for those eligible for vaccination, it should be unequivocally recommended by school nurses as the main vaccination providers as this review has revealed this is an influential motivation in young peoples' decision-making.

REFERENCES

- American Academy of Pediatrics. (2017). Section 3: Summaries of Infectious Diseases, Human Papillomaviruses. Retrieved from https://redbook.solutions.aap.org/chapter.aspx?sectionid=88187200&bookid=1484
- Ames, H.M.R., Glenton, C. & Lewin, S. (2017). Parents' and informal caregivers' views and experiences of communication about routine childhood vaccination: a synthesis of qualitative evidence (review). *Cochrane Database of Systematic Reviews*, 2 Art No. CD011787. DOI: 10.1002/14651858.CD011787.pub2.
- Askelson, N.M., Campo, S., Lowe, J.B., Smith, S., Dennis, L.K. & Andsager, J. (2010). Using the Theory of Planned Behavior to Predict Mothers' Intentions to Vaccinate Their Daughters Against HPV. *Journal of School Nursing*, 26(3), 194-202.
- Australian Government. (2017). *Immunise Australia Program: Human Papillomavirus* (*HPV*). Retrieved from http://www.immunise.health.gov.au/internet/immunise/publishing.nsf/Content/immunisehpv
- Bartlett, J.A., & Peterson, J.A. (2011). The Uptake of Human Papillomavirus (HPV) Vaccine Amongst Adolescent Females in the Invited States A Review of the Literature. *The Journal of School Nursing*, 27(6) 434-446.
- Batista Ferrer, H., Trotter, C., Hickman, M. & Audrey, S. (2014.). Barriers and facilitators to HPV vaccination of young women in high-income countries: a qualitative systematic review and evidence synthesis. *BMC Public Health*, *14*(700), e1-22.
- Bennett, K.K., Buchanan, J.A. & Adams, A.D. (2012). Social-Cognitive Predictors of Intention to Vaccinate Against the Human Papillomavirus in College-Age Women. *The Journal of Social Psychology*, 152(4), 480-492.
- Bernard, D.M., Cooper Robbins, S.C., McCaffery, K.J., Scott, C.M. & Skinner, S.R. (2011). The domino effect: adolescent girls' response to human papillomavirus vaccination. *Medical Journal of Australia*, 194(6), 297-300.
- Bruni, L., Diaz, M., Barrionuevo-Rosas, L., Herrero, R., Bray, F., Bosch, X. ... & Castellsague, X. (2016). Global estimates of human papillomavirus vaccination coverage by region and income level: a pooled analysis. *The Lancet*, 4(7), e453-e463.
- Bynum, S.A., Brandt, H.M., Sharpe, P.A., Williams, M.S. & Kerr, J.C. (2011). Working to close the gap: Identifying Predictors of HPV Vaccine Uptake among Young African American Women. *Journal of Health Care for the Poor and Underserved*, 22(2), 549-561.
- Centers for Disease Control and Prevention. (2016). *HPV Vaccine is Cancer Prevention for Boys too*! Retrieved from https://www.cdc.gov/features/hpvvaccineboys/index.html
- Chao, C., Velicer, C., Slezak, J.M. & Jacobsen, S.J. (2010). Correlates for Human Papillomavirus Vaccination of Adolescent Girls and Young Women in a Managed Care Organization. *American Journal of Epidemiology*, 171(3), 357-367.

- Christy, S.M., Winger, J.G., Raffanello, E.W., Halpern, L.F, Danoff-Burg, S. & Mosher, C.E. (2016). The role of anticipated regret and health beliefs in HPV vaccination intentions among young adults. *Journal of Behavioral Medicine*, 39, 429-440.
- Cooper Robbins, S.C., Brotherton, J.M.L., McCaffery, K. & Skinner, S.R. (2010). "I just signed": Factors Influencing Decision-Making for School-Based HPV Vaccination of Adolescent Girls. *Health Psychology*, 29(6), 618-625.
- Coughlan, M. & Cronin, P. (2017). *Doing a literature review in nursing, health and social care* (2nd ed.). London: Sage Publications Ltd.
- Coughlan, M., Cronin, P. & Ryan, F. (2007). Step-by-step guide to critiquing research. Part 1: quantitative research. *British Journal of Nursing*, *16*(11), 658-663.
- Dempsey, A., Cohn, L., Dalton, V. & Ruffin, M. (2011). Worsening disparities in HPV vaccination among 19-26 year old women. *Vaccine*, 29, 528-534.
- Donadiki, E.M., Jiminez-Garcia, R., Hernandez-Barrera, V., Sourtzi, P., Carrasco-Garrido, P., Lopez de Andres, A. ... & Velonakis, E.G. (2014). Health Belief Model applied to non-compliance with HPV vaccine among female university students. *Public Health*, 128, 268-273.
- Gallagher, K.E., Kadokura, E., Eckert, L.O., Miyake, S., Mounier-Jack, S., Aldea, M. ... & Watson-Jones, D. (2016). Factors influencing completion of multi-dose vaccine schedules in adolescents: a systematic review. *BMC Public Health*, 16, 172.
- Gamble, H.L., Klosky, J.L., Parra, G.R. & Randolph, M.E. (2010). Factors Influencing Familial Decision-Making Regarding Human Papillomavirus Vaccination. *Journal of Pediatric Psychology*, 35(7), 704-715.
- GAVI. (2018). *Human Papilloma Virus Vaccine Support*. Retrieved from http://www.gavi.org/support/nvs/human-papillomavirus/
- Getrich, C.M., Broidy, L.M., Kleymann, E., Helitzer, D.L., Kong, A.S. & Sussman, A.L. (2014). Different models of HPV vaccination decision-making among adolescent girls, parents and health-care clinicians in New Mexico. *Ethnicity and Health*, *19*(1), 47-63.
- Gold, R., Naleway, A. & Riedlinger, K. (2013). Factors Predicting Completion of the Human Papillomavirus Vaccine Series. *Journal of Adolescent Health*, 52, 427-432.
- Goodman-Brown, J. & Gottwald, M. (2008). Public Health Interventions. In J. Mitcheson, (Ed), *Public Health Approaches to Practice* (pp.94-114). Cheltenham: Nelson Thornes Ltd.
- Gottvall, M., Larsson, M., Hoglan, A.T. & Tyden, T. (2009). High HPV vaccine acceptance despite low awareness among Swedish upper secondary school students. *The European Journal of Contraception and Reproductive Health Care*, *14*(6), 399-405.
- Grandahl, M., Larsson, M., Tydén, T, & Stenhammar, C. (2017). School nurses' attitudes towards and experiences of the Swedish school-based HPV vaccination programme A repeated cross sectional study. *PLoS ONE*, *12*(4), e0175883.

- Griffith, R. & Tengnah, C. (2012). Assessing children's competence to consent to treatment. *British Journal of Community Nursing*, 17(2), 87-90.
- Steckler, A., McLeroy, K. R. & Holtzman, D. (2010). Godfrey H. Hochbaum (1916-1999): From Social Psychology to Health Behaviour and Health Education. *American Journal of Public Health*, 100(10), 1864.
- Hodge, F.S., Itty, T., Cardoza, B. & Samuel-Nakamura, C. (2011). HPV Vaccine readiness among American Indian college students. *Ethnicity and Disease*, 21(4), 415-420.
- Hughes, C.C., Jones, A.J., Feemster, K.A. & Fiks, A.G. (2011). HPV vaccine decision making in pediatric primary care: a semi-structured interview study. *BMC Pediatrics*, 11(74), 1-9.
- Kinder, F.D. (2016). Parental Refusal of the Human Papillomavirus Vaccine. *Journal of Pediatric Health Care*, 30(6), 551-557.
- Kwan, T.T.C., Chan, K.K.L., Yip, A.M.W., Cheung, A.N.Y., Young, P.M.C., Lee, P.W.H. & Ngam, H.Y.S. (2008). Barriers and facilitators to human papillomavirus vaccination among Chinese adolescent girls in Hong Kong: a qualitative-quantitative study. *Sexually Transmitted Infections*, 84, 227-232.
- Licht, A.S., Murphy, J.M., Hyland, A.J., Fix, B.V., Hawk, L.W. & Mahoney, M.C. (2010). Is use of the human papillomavirus vaccine among female college students related to human papillomavirus knowledge and risk perception? *Sexually Transmitted Infections*, 86, 74-78.
- Liddon, N.C., Hood, J.E. & Leichliter, J.S. (2012). Intent to receive HPV vaccine and reasons for not vaccinating among unvaccinated adolescent and young women: Findings from the 2006-2008 National Survey of Family Growth. *Vaccine*, 30, 2676-2682.
- Marchand, E., Glenn, B.A. & Bastani, R. (2012). Low HPV Coverage Among Female Community College Students. *Journal of Community Health*, 37, 1136-1144.
- Marchand, E., Glenn, B.A. & Bastani, R. (2013). HPV Vaccination and Sexual Behavior in a Community College Sample. *Journal of Community Health.* 38(6). doi: 10.1007/s10900-013-9710-0.
- Markowitz, L.E., Tsu, V., Deeks, S.L., Cubie, H., Wang, S.A., Vicari, A.S. & Brotherton, J.M.L. (2012). Human Papillomavirus Vaccine Introduction – The First Five Years. *Vaccine*, 30S, F139-F148.
- Mathur, M.B., Mathur, V.S. & Reichling, D.B. (2010). Participation in the Decision to Become Vaccinated Against Human Papillomavirus by California High School Girls and the Predictors of Vaccine Status. *Journal of Pediatric Health Care*, 24(1), 14-24.
- McIntyre, A., Zecevic, A. & Diachun, L. (2014). Influenza vaccinations: older adults' decision-making process. *Canadian Journal of Aging*, 33(1), 92-98.
- Mills, E., Jada, A.R., Ross, C. & Wilson, K. (2005). Systematic review of qualitative studies exploring parental beliefs and attitudes toward childhood vaccination identifies common barriers to vaccination. *Journal of Clinical Epidemiology*, 58, 1081-1088.

- Moher, D., Liberati, A., Tetzlaff, J., Altman, D.G & The PRISMA Group (2009). Preferred Reporting Items for Systematic Reviews and Meta-Analyses: The PRISMA Statement. *Public Library of Science*. 6(7), e1000097, doi: 10.1371/journal.pmed.1000097.
- Moreira, E.D., de Oliveira, B.G., Silva Neves, R.C., Costa, S., Karic, G. & Costa Filho, J.O. (2006). Assessment of Knowledge and Attitudes of Young Uninsured Women toward Human Papillomavirus Vaccination and Clinical Trials. *Journal of Pediatric and Adolescent Gynecology*, 19(2), 81-87.
- Mortensen, G.L. (2010). Drivers and barriers to acceptance of human-papillomavirus vaccination among young women: a qualitative and quantitative study. *BMC Public Health*, 10, 68.
- Nan, X. (2012). Relative Persuasiveness of Gain-Versus Loss-framed Human Papillomavirus Vaccination Messages for the Present and Future-Minded. *Human Communication Research*, 38, 72-94.
- Ogunbajo, A., Hansen, C.E., North, A.L., Okoloko, E. & Niccolai, L.M. (2016). "I think they're all basically the same": parents' perceptions of human papillomavirus (HPV) vaccine compared with other adolescent vaccines. *Child: care, health and development,* 42(4), 582-587.
- Oscarsson, M.G., Hannerfors, A-K. & Tyden, T. (2012). Young women's decision-making process for HPV vaccination. *Sexual and Reproductive Healthcare*, 3, 141-146.
- Petrosky, E., Bocchini, J.A., Hariri, S., Chesson, H., Curtis, C.R., Saraiya, M ... & Markowitz, L.E. (2015). Use of 9-Valent Human Papillomavirus (HPV) Vaccine: Updated HPV Vaccination Recommendations of the Advisory Committee on Immunization Practices. *Morbidity and Mortality Weekly Report, March 27, 2015.* 64(11), 300-304.
- Pluye, P. & Hong, Q.N. (2014). Combining the Power of Stories and the Power of Numbers: Mixed Methods Research and Mixed Studies Reviews. *Annual Review of Public Health*, 39, 29-45.
- Public Health England. (2014). *Human Papillomavirus (HPV): the green book, chapter 18a*. Retrieved from https://www.gov.uk/government/publications/human-papillomavirus-hpv-the-green-book-chapter-18a
- Public Health England. (2015). Human Papillomavirus (HPV) vaccination coverage in adolescent females in England: 2014/15. Retrieved from https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/487514/HP V_2014_15_ReportFinal181215_v1.1.pdf
- Rhodes, D., Visker, J., Cox, C., Forsyth, E., Woolman, K. (2017). Public Health and School Nurses' Perceptions of barriers to HPV Vaccination in Missouri. *Journal of Community Health Nursing*, 34(4), 180-189.
- Rodin, J. & de Ferranti, D. (2012). Universal Health Coverage: the third global health transition? *The Lancet*, *380*(9845), 861-862.

- Rosen, B.L., Ashwood, D., Richardson, D.B. (2015). School Nurses' Professional Practice in the HPV Vaccine Decision-Making Process. *The Journal of School Nursing*, 32(2), 138-148.
- Rosenbloom, S.R. & Killian, C. (2014). What Are They Thinking? Findings for Educators and Practitioners on Youths' Experience and Knowledge of the HPV Vaccine. *American Journal of Sexuality Education*, 9, 41-64.
- Rosenthal, S.L., Weiss, T.W., Zimet, G.D., Good, M.B. & Vichnin, M.D. (2011). Predictors of HPV vaccine uptake among women aged 19-26: Importance of a physician's recommendation. *Vaccine*, 29, 890-895.
- Ryan, F., Coughlan, M. & Cronin, P. (2007). Step-by-step guide to critiquing research. Part 2: qualitative research. *British Journal of Nursing*, *16*(12), 738-744.
- Scarinci, I.C., Harces-Palacio, I.C. & Partridge, E.E. (2007). An examination of acceptability of HPV vaccination among African American women and Latina immigrants. *Journal of Women's Health*, *16*(8), 1224-1233.
- Schuler, C.L., Reiter, P.L., Smith, J.S. & Brewer, N.T. (2011). Human papillomavirus vaccine and behavioural disinhibition. *Sexually Transmitted Infections*, 87(4), 349-353.
- Taddio, A., Chambers, C.T., Halperin, S.A., Ipp, M., Lockett, D., Rieder, M.J. & Shah, V. (2009). Inadequate pain management during routine childhood immunizations: the nerve of it. *Clinical Therapeutics*, 31, Supp. 2, s152-167.
- Tiro, J.A., Tsui, J., Bauer, H.M., Yanada, E., Kobrin, S. & Breen, N. (2012). Human Papillomavirus Vaccine Use Among Adolescent Girls and Young Adult Women: An Analysis of the 2007 California Health Interview Survey. *Journal of Women's Health*, 21(6), 656-665.
- Tong, A., Flemming, K., McInnes, E., Oliver, S. & Craig, J. (2012). Enhancing transparency in reporting synthesis of qualitative research: ENTREQ. *BMC Medical Research Methodology*, 12(181). doi:10.1186/1471-2288-12-181.
- Vanderpool, R.C., Van Meter Dressler, E., Stradtman, L.R., & Crosby, R.A. (2015). Fatalistic Beliefs and Completion of the HPV Vaccination Series Among a Sample of Young Appalachian Kentucky Women. *The Journal of Rural Health*, 31, 199-205.
- Wakimizu, R., Nishigaki, K., Fujioka, H., Maehara, K., Kuroki, H., Saito, T. & Uduki, K. (2015). How adolescent Japanese girls arrive at human papillomavirus vaccination: A semi structured interview study. *Nursing and Health Sciences*, 17, 15-25.
- Walling, E.B., Benzoni, N., Dornfeld, J., Bhandari, R., Sisk, B.A., Garbutt, J. & Colditz, G. (2016). Interventions to improve HPV Vaccine Uptake: A Systematic Review. *Pediatrics*, 138(1), e20153863.

WHO. (2014). Considerations regarding consent in vaccinating children and adolescents between 6 and 17 years old. Retrieved from http://www.who.int/immunization/programmes_systems/policies_strategies/consent_note_ en.pdf?ua=1

- WHO. (2016). *Human Papillomavirus (HPV) and cervical cancer*. Retrieved from http://www.who.int/mediacentre/factsheets/fs380/en/
- WHO. (2017). *Human Papillomavirus (HPV)*. Retrieved from http://www.who.int/immunization/diseases/hpv/en/
- Whittemore, R. & Knafl, K. (2005). The integrative review: updated methodology. *Journal of Advanced Nursing*, *52*(5), 546-553.
- Williams, K., Forster, A., Marlow, L. & Waller, J. (2011). Attitudes towards human papillomavirus vaccination: a qualitative study of vaccinated and unvaccinated girls aged 17-18 years. *Journal of Family Planning and Reproductive Health Care*, 37, 22-25.
- Wright, T. (2011). Consent and Children: A Practical Summary. *The AMA Medical and Legal Journal*, *17*(5), 192-194.
- Zangger Eby, A. (2017). Impacting Parental Vaccine Decision-Making. *Pediatric Nursing*, 43(1), 22-34.