



The knowledge and attitudes of persons who participate and do not participate in colorectal cancer screening: A comparative survey



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1. Introduction

Colorectal cancer poses a major public health challenge, accounting for 10% of all cancer cases on a global scale (Ferlay et al., 2015). Colorectal cancer in Malta, where this study was carried out, is ranked second of all cancers in terms of incidence and mortality in both males and females (Malta National Cancer Registry, 2017). Colorectal neoplasm, however, can be prevented and mortality and morbidity can be drastically reduced if individuals participate in mass screening programmes. This is confirmed by Welch and Robertson (2016) in four trials included in a Cochrane review which showed a 14% reduction in colorectal-cancer mortality and a 5% reduction in colorectal cancer incidence following screening with the faecal occult blood test.

Since 1970 there was a shift in the 5 year survival rate for all stages of both colon cancer and rectal cancer; from 51% to 65% for colorectal cancer and from 48% to 68% for rectal cancer due to early detection and improved treatment (Siegel, De Santis, & Jemal, 2014). However, only 39% of colorectal rectal patients are diagnosed with localized cancer which has a 5 year survival rate of 90% (Siegel et al., 2017). The survival rate declines to 71% and 14% for patients diagnosed with regional and distant stage disease, respectively. These changes are attributable to early detection tests and the timely receipt of high quality treatment. It can no longer be accepted that a tumour that can be diagnosed by screening at an early and surgically treatable stage should continue to cause so many deaths (Altobelli, Lattanzi, Paduano, Varassi, & di Orioa, 2014).

In 2003, the Council of Europe made screening recommendations for colorectal cancer in men and women aged 50–74 at a 1–2-year interval in organised programmes using the faecal occult blood test (Council of the European Union, 2003). In the event of a positive faecal test, clients should be referred for a direct colonoscopy (Council of the European Union, 2003). In order to achieve the required impact on mortality and morbidity, the minimum acceptable participation rate in mass screening programmes is estimated to be 45%, although it is

highly recommended that an uptake rate of 65% should be the goal (Keighley, O'Morain, & Giacosa, 2004).

In January 2013, the Malta National Screening Programme launched colorectal cancer screening on a national level by inviting individuals born between 1949 and 1953 over two years, with a biennial immunochemical faecal occult blood test. As this was a roll-out programme, in 2015–2016, the age range was expanded to include younger and older individuals (those born between 1949 and 1959). Screening uptake was much lower than the minimum 45% in 2013, with an uptake of 36% achieved. This rose to 54% in 2016, but remained well below the ideal 65%, notwithstanding the fact that participation is free and that self-screening using a faecal occult blood test is a non-invasive procedure which does not require any alteration to the person's diet or lifestyle (Malta National Screening Programmes, 2017).

The Health Belief Model provided the theoretical framework for this study in an effort to explain why people choose to, or not to, participate in cancer screening. In line with this model, uptake of screening would depend on the perceived seriousness of the condition (whether the person views colon cancer as being a serious condition), perceived susceptibility to the condition (perceived risk of developing colon cancer, for example when individuals have family members with colon cancer), perceived benefits of action (early diagnosis resulting in decreased mortality), perceived barriers to action (for example, embarrassment, disgust at handling of stools, fear of the results), cues to action (such as adverts in the media, invitations to attend screening and having friends and family receiving colon cancer diagnosis) (Hayden, 2013). An extensive systematic review incorporating 81 papers concluded that, in general terms, constructs from health behaviour models, especially the Health Belief Model, were associated with participation in colorectal screening programmes, even though a minority of studies found no association (Kiviniemi, Bennett, Zaiter, & Marshall, 2011). In a recent cross-sectional study in Seoul (n = 213), logistic regression analysis identified perceived seriousness and perceived barriers as the factors most likely to positively and negatively affect screening

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behaviour respectively (Choi, Jeon, & Kim, 2019).

Previous research identified various specific variables affecting participation in colorectal screening programme. People may choose to participate because they perceive the test as simple and non-invasive, and especially if they appreciate the perceived *benefit* of screening (Molina-Barceló et al., 2014); indeed, higher education levels in general (Choi et al., 2015) and knowledge about colorectal cancer and its screening in particular (Leung, Chow, Lo, So, & Chan, 2016) were associated with improved participation rates. Male gender (So et al., 2012), being subscribed to a health insurance policy (Leung et al., 2016), being a former smoker, having a family history of cancer and being diagnosed with cancer or another chronic illness or serious condition (Choi et al., 2015; So et al., 2012), several of which may be associated with a higher *perceived susceptibility* to cancer, were also associated with better screening rates. Reasons for not participating in colorectal screening included unawareness of the screening programme and the absence of any symptoms of colorectal problems, indicating a low *perceived susceptibility* to colon cancer (Kim, 2018). Results by Wang, Moehring, Stuhr, and Krug (2013) also indicated that fear of cancer (a high perceived severity of colon cancer in terms of the Health Belief Model) could result in the individual taking up the screening invitation. Conversely, worries or fear of receiving a positive screening result as well as anticipated embarrassment or discomfort may lead people to refuse the invitation (Kim, 2018). In the latter case, in terms of the Health Belief Model, the *perceived barriers* to action would outweigh the *perceived benefits* of action. Being advised to get screened for colorectal cancer by a health professional was identified as a particularly effective *cue to action* in several primary studies (Choi et al., 2015; Lee & Lee, 2018; So et al., 2012) and systematic reviews (Kim, 2018; Leung et al., 2016), with one study reporting that Korean Americans who were advised to take a faecal occult blood test by a doctor were fourteen times more likely to do so (Lee & Lee, 2018). Nonetheless, colorectal screening behaviour is also influenced by specific healthcare systems and socio-cultural factors (Kim, 2018; Leung et al., 2016), which underscores the significance of conducting local studies to explore the factors associated with participation in colorectal screening programmes.

In view of the low uptake of colorectal cancer screening in Malta and in various other countries, the present study sought to address the research question ‘What is the difference in knowledge and attitudes and of persons who choose and don't choose to participate in colorectal cancer screening?’ The answer to this question should help to identify strategies which could increase colorectal cancer screening rates to acceptable levels.

2. Methods

2.1. Aim and objectives

The aim of this research study was to compare the knowledge and attitudes between those participating and those not participating in a population-based colorectal cancer screening programme in Malta.

In line with the main components of the Health Belief Model, the objectives were to find differences between the two groups in relation to:

1. Perceived benefits of colorectal cancer screening.
2. Perceived seriousness of colorectal cancer.
3. Perceived susceptibility to colorectal cancer.
4. Fear of colorectal cancer.
5. Prior experience of cancer
6. Barriers to participation in colorectal cancer screening.
7. Knowledge about colorectal cancer
8. The possible association between demographic variables and participation and nonparticipation in colorectal screening.

2.2. Design, setting and sample

A cross-sectional survey design was used in this study with the aim of comparing the knowledge and attitudes of those who had and those who had not taken up the invitation to participate in a mass colorectal cancer screening programme. The target population included the 35,000 individuals born between 1955 and 1959, registered on the National Screening Database in Malta who had been invited to participate in the colorectal cancer mass screening programme for the first time between 2015 and 2016.

Potential participants were randomly selected from the latter database. There are no guidelines at present for the estimation of sample size for the Kruskal-Wallis test which was used in this study to analyse the differences between those who took up and did not take up the invitation for colorectal cancer screening (McDonal, 2014). The aim of this study was to achieve a sample of at least 96 participants in each group assuming a 95% confidence interval and a 10% margin of error for a population of 35,000 (RAOSOFT, 2004). In order to accommodate for non response and ensure that this sample size was achieved, 200 participants were selected from those who had taken up the offer to participate in colorectal cancer screening and 200 clients were randomly selected from those who had not taken up colorectal cancer screening. In view of the lack of research on this particular population it was not possible to estimate possible nonresponse.

2.3. Study measures

The questionnaire used in this study amalgamated two previously developed questionnaires. The first, developed by Domi Le et al. (2013), focused on knowledge, attitudes, beliefs and perceived risks regarding colorectal cancer screening reflecting the principal constructs in the Health Belief Model. In the original study by Domi Le et al. (2013), the Cronbach's alpha was 0.76 for the perceived benefits of screening, 0.87 for perceived susceptibility of developing colorectal cancer and 0.81 for perceived severity of colorectal cancer, indicating good internal consistency reliability for these subscales. In the present study, Cronbach's alpha was much lower than the expected 0.70 with perceived benefits of colorectal screening scoring 0.57, perceived susceptibility for colorectal cancer 0.50 and perceived severity of colorectal cancer 0.48, suggesting low internal consistency for the subscales.

The second was a questionnaire developed by Champion et al. (2004) which focused on fear of breast cancer and was later adapted to focus on fear of colorectal cancer by Leung, Wong, and Chan (2014). Leung et al.'s (2014) version of the scale was added to the questionnaire since the Health Belief Model has been criticised with regards to its lack or inadequate attention to emotions such as fear when making health related decisions (Taylor et al., 2007). Leung et al. (2014) adapted the breast cancer tool to colorectal cancer. Cronbach's alpha for the scale was 0.95, and test-retest reliability was $r = 0.52$. In the present study, this scale had a Cronbach's alpha of 0.85 indicating that the items measuring this dimension had good internal consistency (Tavakol & Dennick, 2011).

In view of the Maltese population being bilingual, with some individuals being primarily English speakers whilst others being primarily Maltese speakers, both English and Maltese versions of the questionnaire were sent to the participants. Translation of the questionnaire was performed following testing for internal consistency reliability and using standard regulations of the World Health Organisation protocol of translation (World Health Organisation (WHO), 2017).

2.4. Data collection procedures

In view of data protection legislation, the questionnaires were sent out by post to the participants by an intermediary person who had access to the National Screening Database. The subjects were asked to fill in an anonymous questionnaire and return it in a self-addressed, pre-

paid postage envelope. Data collection took place between mid-September 2016 and the end of October 2016; reminder questionnaires were sent out twice at approximately two-week intervals in an attempt to achieve as high a response rate as possible.

2.5. Ethical considerations

Permission to carry out this study was obtained from the University of Malta Research Ethics Committee. The main ethical issues in this study were those of obtaining informed consent and ensuring anonymity. Informed consent was viewed to be indicated when participants completed and returned their questionnaire. Responses were completely anonymous with no way to identify who had answered the questionnaire. An intermediary person was included in the data collection procedure to ensure that the researcher did not have access to personal information on the participants, thus respecting data protection regulations.

2.6. Data analysis

Data analysis was carried out using the SPSS Statistics software version 24. The differences in knowledge and attitudes between those who had/had not undergone screening were analysed using the Chi-squared test, and the Mann-Whitney *U* test Results were considered to be statistically significant if the *p* value was below 0.05.

3. Results

A total of 245 persons participated in the study with a 61% overall response rate. Of the latter, 166 (83% of the 200 invitees) had undergone screening and 79 (40% of the 200 invitees) had not participated in the screening programme. The response rate for those who had chosen not to undergo screening was consequently much lower than for those who had chosen to undergo screening and did not reach the estimated required sample size of 96 subjects. The demographic characteristics of the respondents in this survey are presented in Table 1.

Table 1
The demographic characteristics of the participants in the study.

	Underwent screening	Did not undergo screening
Gender		
Males	68(41%)	37(47%)
Females	98(59%)	42(53%)
Age		
57	36(21%)	16(20%)
58	36(21%)	19(24%)
59	28(17%)	19(24%)
60	48(30%)	14(18%)
61	18(11%)	11(14%)
Education		
Primary level	45(27%)	16(20%)
Secondary level	85(51%)	46(58%)
Post-secondary level	27(16%)	13(17%)
University degree	9(6%)	4(5%)
Living status		
Alone	15(9%)	5(6%)
Living with others	151(91%)	74(94%)
Occupation		
Full time employment	67(41%)	33(42%)
Part-time employment	12(7%)	10(13%)
Housework	17(10%)	14(16%)
Take care of family members	34(21%)	9(11%)
Pensioner	21(13%)	7(9%)

3.1. The association between demographic variables and participation and nonparticipation in colorectal screening

The Shapiro-Wilk test was used to check for normality. The results showed non-normal distribution of data; non-parametric tests were consequently used. Descriptive analysis was carried out to compare participants and non-participants in the screening programme in terms of demographic characteristics such as gender, age, education, modes of living and employment. There were 68 males (41%) and 98 females (59%) who had participated in the screening programme and 37 males (47%) and 42 females (53%) had not participated in screening. There was no significant association between gender and participation/non-participation in colorectal cancer screening ($\chi^2 (5) = 0.39, p = .75$). The Chi-Squared test also did not identify any statistically significant difference in relation to the employment status of those who had or had not participated in the screening programme ($\chi^2 (5) = 7.31; p = .20$).

A descriptive analysis was carried out on whether participants were living alone or with someone. Overall, most of the study participants ($n = 225; 92%$) lived with someone. Only 15 (9%) of screening participants and five (6%) of non-participants lived alone. There was no significant association between living arrangements and participation in colorectal cancer screening ($\chi^2 (1) = 0.52, p = .47$). The age range of study participants was between 57 and 61 years. Participation in the screening programme was not significantly associated with age ($\chi^2 (4) = 4.70, p = .32$).

The Chi-Squared test was used to assess any differences on the basis of educational background, which ranged from primary to tertiary education. There were no significant differences between the participants and non-participants with regard to educational level ($\chi^2 (3) = 1.36, p = .72$).

3.2. Knowledge about colorectal cancer

Almost all the participants ($n = 241; 98%$) understood the concept of early diagnosis. Most ($n = 212; 86%$) also accurately knew that there are several types of cancer and 235 (96%) believed that some cancers can be cured. Although, these are considered to be positive results, 124 (51%) believed that cancer is a fatal disease. The fact that exercise could prevent many cancers was correctly indicated by only half the participants ($n = 119; 49%$). Most participants were aware of the hazards of smoking ($n = 210; 86%$) and that fruit and vegetables could prevent many cancers ($n = 196; 80%$) and 178 (73%) correctly understood that more than half the individuals diagnosed with colorectal cancer survive for over five years.

Knowledge about symptoms of colorectal cancer was also assessed (Table 2). Only 111 (45%) correctly believed that abdominal pain could be a symptom. Bloody stools were correctly identified as a symptom by

Table 2
Mann-Whitney Test comparing colorectal cancer screening participation.

Subscale	Mean score (s.d.) participants	Mean score (s.d.) non-participants	Mann-Whitney <i>U</i> test (p-value)
Perceived benefits of colorectal screening	20.70 (3.63)	19.76 (3.95)	5634.00 (p = .07)
Perceived severity of colorectal cancer	35.16 (5.26)	34.25 (5.53)	6093.50 (p = .37)
Perceived susceptibility to colorectal cancer	11.83 (3.15)	11.80 (2.77)	6397.00 (p = .76)
Fear related to colorectal cancer	21.30 (6.91)	22.47 (5.92)	6007.50 (p = .29)
Prior experience with cancer	7.01 (2.29)	6.46 (2.37)	5720.00 (p = .10)
Knowledge on colorectal cancer	13.33 (2.29)	12.73 (2.40)	5743.50 (p = .11)
Barriers to participate in screening	8.84 (3.27)	10.38 (3.40)	33,180.00 (p = .004)

most of the study participants ($n = 226$; 92%), whilst an equal number of participants 226 (92%) incorrectly thought that burning stomach aches was a symptom. Only 130 (53%) correctly answered that diarrhoea/constipation could be a symptom of colorectal cancer. The largest number of participants ($n = 232$; 95%) incorrectly thought that difficulty in swallowing was a symptom. Conversely, only 113 (46%) correctly believed that fatigue could be a symptom. Only, 67 (27%) correctly identified that being pale is a symptom, and 125 (51%) correctly stated that incomplete emptying of the bowel could be a symptom of colorectal cancer. A headache was incorrectly thought to be a symptom by 231 (94%) of the participants. Weight loss was correctly identified by 125 (51%) as a symptom and 128 (52%) identified pain during defecation as a symptom.

3.3. Comparison of perceived benefits of screening, seriousness and susceptibility of colorectal cancer, prior experience of cancer and barriers to participation in screening

The main significant difference between screening responders and non-screening responders was in relation to barriers to participate in screening ($U = 33,180.00$; $p = .004$) (Table 2). This section included items on the fear of finding that something was wrong and embarrassment to perform the test. It also included the issue of being symptomless when asked to perform the test and lack of time as reasons for not performing the test. In terms of the Health Belief Model, these items reflect the concepts of perceived susceptibility to colorectal cancer and high perceived barriers to action.

There were no other significant differences in relation to perceived severity and susceptibility to colorectal cancer, fear of colorectal cancer, and perceived benefits of screening between those who participated or did not participate in colorectal screening.

4. Discussion

Participation in colorectal screening is increasing slowly in Malta; in 2016, the participation rate was 54% ($n = 11,711$), whereas in the Netherlands, for example, it was 71.3% (European Commission, 2017; Malta National Screening Programmes, 2017). The current participation rate is still considerably lower than the 65% participation rate which is required to make screening worthwhile (von Karsa, Patnick, & Segnan, 2012). Screening becomes relevant when it saves lives, but for this to be achieved, high rates of participation should be attained, together with screening efficacy to reduce mortality.

4.1. The association between demographic characteristics and colorectal cancer screening behaviour

4.1.1. Knowledge about colorectal cancer

In terms of perceived susceptibility of developing colon cancer, the present study yielded varied results. Although the lifetime risk of developing colorectal cancer is 13% (Ferlay et al., 2015), this was matched by the perception of only 36 (15%) of the respondents. This result shows the importance of creating more awareness of the risks of colorectal cancer, which could act as a cue to action for taking part in the screening programme, as most participants in the questionnaire were misinformed about this condition. A substantial amount ($n = 118$; 48.2%) of respondents believed that cancer is a fatal disease, showing that cancer is perceived as a disease with serious outcomes. In a meta-analysis, Wolin, Yan, Colditz, and Lee (2009) identified that 24% of the individuals can reduce their colon cancer risk through participation in physical activity; nonetheless, only half the respondents of the current study ($n = 123$; 50.2%) knew about the benefits of exercise for colon cancer prevention. Campaigns on the hazards of smoking have apparently conveyed the message as most of the participants ($n = 210$; 86%) knew about the dangers of tobacco on cancer risk. There was also considerable awareness on the benefit of healthy eating ($n = 196$;

80%). These two lifestyle behaviours, smoking and a healthy diet, have been widely presented to the public, and the information in this regard is generally accepted. Colorectal cancer screening improves the prognosis in both genders. When analysing data of perceived benefits of colorectal screening by gender, no difference was found, indicating that gender is not a particularly influential issue in colorectal cancer screening participation.

4.1.2. Comparison of perceived benefits of screening, seriousness and susceptibility of colorectal cancer, prior experience of cancer and barriers to participation in screening

In the present study, there were no differences between participants and non-participants in their perception of the severity of colorectal cancer. The seriousness of the disease was understood even by non-participants. Possible reasons for the latter findings are that the screening invitation includes a booklet with extensive information beyond the faecal immunochemical test which the participants are expected to carry out. Information about the colonoscopy procedure with all its complications is also included, which may put persons off participating in screening, thereby acting as a barrier to action. Conversely, it appears that participants did not actually pay much attention to certain information provided in the booklet; most participants were not adequately knowledgeable about the symptoms of colorectal cancer, even though these were listed in the booklet they had received at home with the invitation to participate in the screening programme.

Fear of developing colorectal cancer can act both as a cue and as a barrier to participation. Leung et al. (2014) state that colorectal cancer screening participation is accompanied by barriers instigated by fear. Fear can be termed as a negative emotion complemented by a high level of physiologic arousal stimulated by a threat that seems substantial and personally meaningful. Whilst fear of cancer should have increased the perceived susceptibility and seriousness of the condition, the barriers to screening, such as the possible disgust perceived in carrying out the test and fear of finding that something is wrong, seem to have outweighed the former in individuals who declined the invitation to participate in the screening programme.

Cancer is associated by most individuals with pain and death. Sometimes, the mere mention of the word can cause distress and anxiety (Nelson, 2014). In some instances, familiarity with, and knowledge of a previous cancer experience involving family and loved ones can bring about negative feelings and memories that may have an impact on one's life and health related decisions (Zabora, BrintzenhofeSzoc, Curbow, Hooker, & Piantadosi, 2001). Conversely, individuals who have no experience of friends or relatives with cancer, might react differently to a screening invitation as they may not have the same perception of susceptibility to the condition. The emotions of a prior experience with cancer were measured in the questionnaire. No significant difference was found between participants and non-participants in terms of having previous experience of cancer. Emotion has long been believed to affect decision-making, although this aspect is not formally included in the Health Belief Model. Individuals may adopt an antagonistic style by avoiding uncertainty, and potential threats such as colorectal cancer screening.

There was a significant difference between participants and non-participants in terms of perceived barriers to participate in screening. This was an important finding as it was the only difference between participants and non-participants. Non-participants were not willing to know their health status and were hesitant to the idea of screening. As mentioned earlier, more than half the participants ($n = 132$; 53%) had a lower perception of their risks. People might consider themselves not to be susceptible to colon cancer and so do not take the necessary steps to undergo screening. A strong negative predictor that affects screening is anxiety or the absence of trust in screening effectiveness (Sung et al., 2008). A perceived lack of time may also contribute to such barriers to action in terms of screening participation.

4.1.3. Recommendations for screening practice

In view of these results indicating barriers to action, colorectal neoplasm mass screening programmes should emphasize that identifying that something is wrong at an early stage is positive not negative. Barriers to participation can be reduced by providing equipment such as gloves with the faecal occult blood kit to help the person overcome their reluctance to handle the stools. The person should also be informed that a lack of symptoms does not mean that precursor lesions are not present and that the test only takes a few minutes to perform. To reduce the barriers to action, the information provided should focus only on the faecal occult blood test and should not include information on colonoscopy until a positive faecal occult test result is obtained and the next step of screening is actually required. The information on complications of colonoscopy and its invasive nature could needlessly provide a barrier to action.

4.1.4. Strengths and limitations of the study

Whilst a very good response rate was obtained for participants who had taken up screening (83% of the 200 invitees), the response rate for those who had not taken up screening was very low (40% of the 200 invitees). This may mean a lack of representativeness of the latter which may have influenced the results of this study; it is possible that respondents and nonrespondents were different, particularly since the nonrespondents had already shown a lack of interest in colorectal screening. This is one of the main limitations of the study as this may have resulted in possible lack of statistical power which could explain the lack of a difference between those who participated and did not participate in screening on many aspects of the Health Belief Model; in view of this the results of this study may not be generalisable. This low response rate was achieved notwithstanding the many inbuilt initiatives taken to achieve as high a response rate as possible, including multiple reminders and the provision of stamped self-addressed envelopes. The study also included the questionnaire in both Maltese and English with the aim of decreasing the risk of nonparticipation due to language barriers.

The tool in the Maltese language was assessed for validity using forward and back translation. There is however no assurance that the interpretation of the items in the tool were equivalent for the English and the Maltese speakers due to nuances in the Maltese and English language. The Maltese version of the tool was also not tested for internal consistency reliability.

This paper focused on applying the Health Belief Model to participation in colorectal screening behaviour. The Health Belief Model is limited in that it focuses on individual factors and does not account for factors external to the individual such as the influence of friends and family, community and policy related factors. This study reported in this paper was a cross-sectional survey; however, a systematic review by Kiviniemi et al. (2011) showed that for the “severity” component of the HBM, longitudinal studies were significantly more likely to be associated with colorectal screening behaviour ($\chi^2(1) = 5.92, p = .04$), which in turn may have affected the results.

5. Conclusion

In the study carried out there was no significant difference in knowledge, the understanding of severity of the disease, knowledge of the benefits of screening, between persons who had participated and not participated in a colorectal screening programme; yet, this did not translate into action, that is participation in colorectal screening. The main finding was that those who did not participate reported a higher perception of barriers to action, explaining the lack of an effect of understanding and knowledge about colorectal cancer and the benefits of screening. In view of this, colorectal neoplasm mass screening programmes should try to counteract these perceived threats and barriers by emphasizing that identifying that something is wrong at an early stage is positive and not something to fear. The provision of equipment

such as gloves may help the person overcome their reluctance to handle the stools. They should also be informed in the literature sent to their home that the lack of symptoms does not mean that precursor lesions are not present. Information in the initial stages of screening should focus only on the test being performed at that time to avoid the perceived threat of undergoing a colonoscopy when this may not be required at all. It should be explained that the test for identification of faecal occult blood is not invasive and takes only a few minutes to perform.

Declaration of Competing Interest

Ms. Sylvia Camilleri is employed within the National Screening Agency where this study was conducted.

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