

Appendix 58: Critical Appraisal of the Included Studies: Qualitative (Question 7)

First Author Year of Publication, Study Design, Data Collection Methods	Strengths	Limitations
<p>Burton-Chase 2014,²²² Qualitative Description, Interview, Questionnaire</p>	<ul style="list-style-type: none"> Data collection strategies were well described, and congruent with the research questions. Interviews adequately addressed the need to seek patient perspectives, while questionnaire provided opportunity to gain demographic information and knowledge of cancer risk. Data analysis strategies were well described. The two coders had a high level of agreement, and met to discuss discrepancies and emerging themes. Additionally, verbatim data to support the coding analysis was provided. 	<ul style="list-style-type: none"> The authors describe how eligible patients were identified, but it is unclear if participants were all participants in the registry, or only a subset. There is no description of when sampling stopped, and whether this was guided by data saturation, or convenience, for example. Much of the qualitative data were enumerated, which is not appropriate given the sampling strategy. It is clear that themes and concepts were rooted in the data; however, it is unclear if the full range of themes were reported. The analysis instead focused on identifying the number of participants who raised certain concepts, but it is unclear if the diversity within issues is covered. There was little discussion of non-disclosure practices with reasons, which is relevant to the objectives and likely included in the data but not reported. The role of the researcher is not described; nor have the researchers' assumptions and biases in particular relation to the research question been made explicit. No techniques described to enhance dependability.
<p>Tomiak 2014,¹⁷⁸ Qualitative description, Interview</p>	<ul style="list-style-type: none"> Study design and research questions clearly described and justified. Reporting of verbatim data and independent analysis by more than one researcher used as techniques to enhance credibility of data and analysis. 	<ul style="list-style-type: none"> Unclear how study participants were selected from the target population. Unclear whether data collection and sampling occurred until data saturation was reached. Data collection strategy was poorly described. Unclear where data collection took place, what was included in the interview guide, how long the interviews lasted, and whether interviews were semi-structured or otherwise.

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		<ul style="list-style-type: none"> • Unlikely that diversity in perspectives on the issue of uptake of genetic counselling and testing could be explored, given the small sample and underrepresentation of decliners. • The role of the researcher is not described; nor have the researchers' assumptions and biases in particular relation to the research question been made explicit. • No techniques reported to enhance dependability of data or the data analysis.
Bruwer 2013, ¹⁶³ Qualitative description, Interview, Observation	<ul style="list-style-type: none"> • Data collection strategies are well described, and congruent with the research questions. • Analysis strategy is well described, and reported results are clearly supported by data, and from the perspective of participants. • Coding and theme development confirmed by two supervisors, although no description was provided of the process or results of this exercise. Additionally, verbatim data to support the coding analysis were provided. 	<ul style="list-style-type: none"> • "Information-rich" participants were reported to be identified, although no description was provided of what is meant by "information-rich" in this context, or how people were identified. Ideally, participants would have reflected the range of potential emotional effects and familial communication patterns, although it is not clear if that is the case. • A thematic analysis is well described, although most of the reported data are in the form of frequency and counts. Frequency and counts, suggestive of generalizability or representativeness, are not appropriate for the sampling strategy, suggesting a high potential for biased estimates. • The role of the researcher is not described; nor have the researchers' assumptions and biases in particular relation to the research question been made explicit. • No techniques described to enhance dependability.
Shipman 2013, ¹⁷⁶ Qualitative description, Interview	<ul style="list-style-type: none"> • Study design and research questions were clearly stated and justified. • Sampling strategy was well defined and congruent with research questions. • Data collection and analysis strategies were well described and congruent with research questions. 	<ul style="list-style-type: none"> • Unclear if data collection and sampling continued until data saturation was reached.

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	<ul style="list-style-type: none"> • Results are well rooted in participant perspectives and a diversity of perspectives was accounted for. • Limited description provided regarding co-construction of accounts of responsibility, between interviewer and participant. • Analysis by more than one researcher, and verbatim reporting of data used as strategies to enhance credibility. • Peer review as a strategy to enhance dependability. 	
Walsh 2012, ¹⁸⁵ Qualitative description, Focus group	<ul style="list-style-type: none"> • Study design and research questions clearly described and justified. • Data collection and analysis strategies are clearly reported and congruent with the research objectives. • Reporting of verbatim data and independent analysis by more than one researcher used as techniques to enhance credibility of data and analysis. 	<ul style="list-style-type: none"> • Unclear whether a purposive sampling strategy was used, or how study participants were recruited and selected. • Unlikely that sampling and data collection occurred until data saturation was reached. • While it is likely that participant perspectives are reflected in the report, there is indication of the researcher's voice taking precedence over the patient's voice. • The role of the researcher is not described; nor have the researchers' assumptions and biases in particular relation to the research question been made explicit. • No techniques reported to enhance dependability.
Watkins 2011, ²⁰⁸ Grounded theory, Interview	<ul style="list-style-type: none"> • Study design and research questions were clearly stated and justified. • Sampling occurred until data saturation was reached. • Data collection and analysis strategies well described and congruent with research questions. • Results are well rooted in participant perspectives and a diversity of perspectives was represented. 	<ul style="list-style-type: none"> • Sampling strategy is poorly reported, although it does seem that some sampling decisions were based on emerging theories, as is appropriate for a grounded theory approach. Participants were selected from a prior case-control study with no description of the purposive strategy used. Unclear how of 17 eligible families, 39 people could be included, but ultimately there were 23 participants.

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	<ul style="list-style-type: none"> Member checking and independent analysis by more than one researcher used as strategies to enhance credibility. Peer review used as strategy to enhance dependability. 	<ul style="list-style-type: none"> The role of the researcher is not described; nor have the researchers' assumptions and biases in particular relation to the research question been made explicit.
Ersig 2010, ²⁵¹ Qualitative description, Interview	<ul style="list-style-type: none"> The study design is congruent with the research question, although no justification is reported. 	<ul style="list-style-type: none"> It appears that a representative sample was chosen, although a purposive sample would have been more appropriate for the research question. There was no mention of whether sampling continued until data saturation. Data collection process is poorly described; for example, it is not reported who conducted the interviews or how long they lasted. The role of the researcher is not described; nor have the researchers' assumptions and biases in particular relation to the research question been made explicit. No techniques were reported to enhance the credibility or dependability of the results.
Palmquist 2010, ¹⁶⁵ Qualitative description, Interview	<ul style="list-style-type: none"> Purposive sampling strategy well described, and congruent with research questions. Data collection and analysis strategies well described and congruent with research questions. Results are consistent with data and rooted in participants' perspectives. Credibility enhanced through independent analyses by more than one researcher and the reporting of verbatim data. 	<ul style="list-style-type: none"> Study design not clearly stated or justified. Unclear if sampling and data collection continued until saturation. Given that diversity in racial backgrounds drove sampling decisions, more cross-cultural comparisons would have been appropriate. The role of the researcher is not described; nor have the researchers' assumptions and biases in particular relation to the research question been made explicit. No strategies to enhance dependability were reported.
Landsbergen 2009, ¹⁹⁴ Qualitative description, Interview, Chart Review	<ul style="list-style-type: none"> Research questions were clearly stated and suited to qualitative inquiry Data collection strategies are well described and congruent with research objectives. 	<ul style="list-style-type: none"> Study design not described nor justified. Sampling strategy is clearly defined, but excludes people who are MSI negative whose perspectives would have been informative for the research question. Further, sampling did not continue until data saturation was reached.

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		<ul style="list-style-type: none"> • Data analysis strategies are poorly described, and raise issues regarding congruence with the research questions, how themes were developed, and whether the diversity of perspectives were appropriately captured. • The role of the researcher is not described; nor have the researchers' assumptions and biases in particular relation to the research question been made explicit. • No techniques were reported to enhance credibility or dependability of the data or data analysis.
McCann 2009, ¹⁸⁶ Qualitative description, Interview	<ul style="list-style-type: none"> • Study design and research questions clearly stated, justified, and congruent. • Data collection and data analysis strategies are well described. • Results are well rooted in participant perspectives, verbatim quotes are provided to support data analysis, and a diversity of perspectives are accounted for and reported. • Independent analysis of 4 transcripts by a separate researcher to enhance credibility. 	<ul style="list-style-type: none"> • No techniques were reported to enhance the dependability of the results. • Sampling strategy is not well described and therefore unclear if strategy is congruent with research question. Medical records were used to determine eligibility, but no description was provided of how people were chosen from among the eligible individuals. • Unclear if sampling continued until data saturation, or how otherwise the sample size was determined. • The role of the researcher is not described; nor have the researchers' assumptions and biases in particular relation to the research question been made explicit.
Roygnan 2008, ²⁰⁴ Qualitative description, Interview	<ul style="list-style-type: none"> • Research questions were clearly stated and suited to qualitative inquiry. • Results are well rooted in participant perspectives, and a diversity of perspectives are accounted for and reported. 	<ul style="list-style-type: none"> • Unclear whether ethics approval was obtained. • Sampling strategy is poorly described, in terms of sample size, selection criteria and recruitment. • Unlikely that sampling and data collection occurred until data saturation was reached. • Data collection and data analysis strategies are poorly reported, making critical appraisal difficult. • The role of the researcher is not described; nor have the researchers' assumptions and biases in particular relation to the research question been made explicit. • No techniques reported to enhance credibility or dependability of data or the data analysis.

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Carlsson 2007, ²⁰⁵ Qualitative description, Interview	<ul style="list-style-type: none"> • Study design and data collection well justified and appropriate to evaluate experiences from and perceived impact on life after genetic testing. • Sampling strategy well described and justified, although no indication provided as to whether sampling continued until data saturation. • Data collection and analysis strategies well described and justified. • Themes and subthemes with supportive data outlined in a comprehensive table, suggesting data are rooted in participants' perspectives and diversity in perspectives has been explored. 	<ul style="list-style-type: none"> • The role of the researcher is inadequately explored. Prior experience with the topic, and qualitative research, should have been outlined to explore assumptions and biases and the potential influence on data collection and analysis. • No techniques to enhance dependability were reported.
Wakefield 2007, ¹⁶⁸ Qualitative description, Questionnaire, Chart review	<ul style="list-style-type: none"> • Study design and research questions clearly described and justified. • Data collection and analysis strategies are clearly reported and congruent with research objectives. • Results are rooted in participants' own perspectives, and diversity in perspectives was explored. • Reporting of verbatim data and independent analysis by more than one researcher used as techniques to enhance credibility of data and analysis. • Peer debriefing used as a technique to enhance dependability. 	<ul style="list-style-type: none"> • Unclear whether ethics approval was obtained. • Unclear whether sampling and data collection occurred until data saturation was reached. • The role of the researcher is not described; nor have the researchers' assumptions and biases in particular relation to the research question been made explicit.
Mesters 2005, ²¹⁹ Qualitative description, Interview	<ul style="list-style-type: none"> • Study design was well justified and congruent with research questions. • Data collection and analysis strategies are well described and congruent with research questions. • Results are well rooted in participant 	<ul style="list-style-type: none"> • Unclear if ethics approval was obtained. • Sampling strategy is incongruent with the research question. A random sample was obtained, although it would have been more appropriate to select registry participants based on characteristics that could influence disclosure, such as age, children or no

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	<p>perspectives, and a diversity of perspectives was explored in the analysis.</p> <ul style="list-style-type: none"> • Credibility enhanced through independent analyses by more than one researcher and the reporting of verbatim data. 	<p>children, sex, psychological distress, social support, and ensure variation in these characteristics in the sample. Further, no rationale was provided for target sample size of 30, nor was a description provided regarding data saturation.</p> <ul style="list-style-type: none"> • The role of the researcher is not described; nor have the researchers' assumptions and biases in particular relation to the research question been made explicit. • No strategies to enhance dependability were reported.
<p>Pentz 2005,²³¹ Qualitative description, Interview</p>	<ul style="list-style-type: none"> • Study design was well justified and congruent with research questions. • Results were rooted in participants' own perspectives and a diversity of perspectives was explored. • Credibility enhanced through independent analyses by more than one researcher and the reporting of verbatim data. • Peer review conducted to enhance dependability. 	<ul style="list-style-type: none"> • Sample was recruited from another research study; therefore, not purposively developed to address this research question. • Limited detail was provided regarding data collection; for example, who conducted the interviews, how long they were, where they took place, or what questions were asked. • Unclear if data saturation was reached. • Limited detail was provided regarding data analysis; for example, how codes were developed and applied. • Qualitative data were quantified in the analysis, which resulted in lost meaning. • The role of the researcher is not described; nor have the researchers' assumptions and biases in particular relation to the research question been made explicit.
<p>Koehly 2003,²²¹ Qualitative design using Social Network Methodology, Interview</p>	<ul style="list-style-type: none"> • Study design and research questions clearly described and justified. • Sampling strategy clearly described and justified. • Data collection and analysis strategies were clearly described and justified. 	<ul style="list-style-type: none"> • Recruitment was conducted through another research study, and therefore didn't allow for sampling until data saturation was reached. • Unclear whether diversity in perspectives related to familial discussions about genetic testing could be explored in 5 families and whether it is captured in the reported analysis. • The role of the researcher is not described; nor have the researchers' assumptions and biases in particular relation to the research question been made explicit.

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Peterson 2003, ¹⁶⁶ Qualitative description, Interview	<ul style="list-style-type: none"> • Study design was well justified and congruent with research questions. • Data collection and analysis strategies are well described and congruent with research objectives. • Results were rooted in participants' own perspectives. • Researcher assumptions and biases are described as they related to the research question. • Credibility enhanced through independent analyses by more than one researcher and the reporting of verbatim data. • Peer review conducted to enhance dependability. 	<ul style="list-style-type: none"> • No techniques reported to enhance credibility or dependability of data or the data analysis. • Sampling strategy was not well described. Participants were recruited from an ongoing clinical study, but it is unclear if all eligible families were included or a subset. If a subset, it is unclear how they were selected. • Unclear if data saturation was reached. • Unclear if diversity in perspectives were explored, as in most cases, results were described as if all families agreed.
Ramsey 2003, ¹⁹⁰ Qualitative description, focus group	<ul style="list-style-type: none"> • Study design and data collection methods are well described and justified. 	<ul style="list-style-type: none"> • Sampling strategy is not well described, as it is unclear how study participants were selected from those in the registry. • It is unlikely that a purposive sample was obtained. Matching by age and sex would likely not achieve diversity in perspectives. • Unlikely that data saturation was reached, given the sampling strategy and description of the approach. • Unlikely that participant concerns, versus researcher concerns, were adequately addressed. • Unclear how themes were developed, and whether initial impressions were subsequently verified against data. • The role of the researcher is not described; nor have the researchers' assumptions and biases in particular relation to the research question been made explicit. • No techniques to enhance dependability or credibility

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Reeve 2000, ¹⁹³ Qualitative description, Interview	<ul style="list-style-type: none"> • Study design and research questions were clearly stated and justified. • Sampling strategy well described, and congruent with the research questions. Sampling continued until data saturation was reached. • Data collection and analysis strategies were well described and congruent with the research question. • Results are well rooted in participant perspectives, and a diversity of perspectives was accounted for. • Member checking and independent analysis by more than one researcher conducted to enhance credibility. 	<p>of the data were reported.</p> <ul style="list-style-type: none"> • Unclear if ethics approval was obtained. • The role of the researcher is not described; nor have the researchers' assumptions and biases in particular relation to the research question been made explicit. • No techniques reported to enhance dependability.
Lynch 1999, ¹⁷¹ Unclear, Interview	<ul style="list-style-type: none"> • No major strengths identified. 	<ul style="list-style-type: none"> • Study design and research questions are not described, nor justified. • No details are provided regarding how the 7 families in the sample were selected and recruited. • Data collection strategies are not well reported. Unclear when interviews took place — perhaps during clinical counselling sessions. • No details regarding the data analysis plan were provided, raising concerns regarding how themes were identified, whether results represent participant perspectives, and whether a diversity of perspectives have been explored. • The role of the researcher is not described; nor have the researchers' assumptions and biases in particular relation to the research question been made explicit. • No techniques reported to enhance credibility or dependability of data or the data analysis.

CRC = colorectal cancer; MSI = microsatellite instability.