


BMJ Open Lifestyles and determinants of perceived health in Italian grown-up/adult congenital heart patients: a cross-sectional and pan-national survey

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ABSTRACT

Objectives To provide the first epidemiological lifestyle descriptions of the Italian grown-up/adult congenital heart disease (GUCH/ACHD) population by identifying the determinants of poor perceived health status.

Design Cross-sectional pan-national survey.

Setting Italian GUCH/ACHD patients who were members of the Italian Association of GUCH/ACHD.

Primary and secondary outcome measures To discuss these lifestyle descriptions through an ad hoc developed questionnaire and health perceptions (ie, mental and physical health perception) through a short form health survey (SF-12).

Results 629 patients included; many investigated GUCH/ACHD lifestyles were determined similar to those of the general population — with the exception of the smoking habits, which were lower. The odds of the occurrence of inadequate physical health perceptions increased by more than two times in patients undergoing antiarrhythmic therapies (OR adjusted=2.045; 95% CI=1.201 to 3.479; p=0.008; n=629), more than 1.5 times in patients taking oral anticoagulants (OR adjusted=1.638; 95% CI=1.038 to 2.585; p=0.034; n=629) and roughly 1.7 times in patients treated with antiplatelets (OR adjusted=1.743; 95% CI=1.024 to 2.966; p=0.041; n=629). The odds of the occurrence of inadequate mental health perceptions increased by 1.7% for every year that the patients aged (OR adjusted=1.017; 95% CI=1.002 to 1.032; p=0.025; n=629).

Conclusion Particular attention should be paid to these ageing patients' increasing psychological needs, and additional research is needed to identify associations between their lifestyles and clinical outcomes.

INTRODUCTION

Roughly 85% of children with congenital heart disease (CHD) live to adulthood and thus represent the population of grown-up/adult congenital heart disease (GUCH/ACHD) patients.¹ More precisely, the GUCH/ACHD rate has been growing steadily, even if accurate data on the size and characteristics of this population remain lacking.² Even if the large variety of CHD and its clinical problems

Strengths and limitations of this study

- The study results require caution regarding their generalisation, as lifestyle trajectories over time were not described due to the cross-sectional approach taken for the data collection process.
- The self-report approach taken during the clinical information collection requires caution, as a direct assessment of the respondents' actual clinical conditions was not performed to collect data.
- The sampling was performed using the contacts of the Italian Association of grown-up/adult congenital heart disease (AICCA); therefore, a slight overestimation of the healthy lifestyle is possible, acknowledging that the AICCA patient-members may become more engaged in their treatment than may other patients.
- The questionnaire used in this survey to investigate lifestyles (ad hoc developed questionnaire) was validated for content and face validity, while the questionnaire that investigates health perceptions possesses well-known validity properties (SF-12).
- The surveyed patients equally represent Northern, Central and Southern Italy.

require specific focus for improving the GUCH/ACHD clinical condition, this population also shares a number of important communalities mainly related to the modifiable risk factors of a decline in clinical status. Among these modifiable risk factors, lifestyle plays a pivotal role in improving the overall health conditions associated with GUCH/ACHD.³ Further, the descriptions of these patients' socio-demographic and clinical determinants of their perceived health statuses play a paramount role in framing a comprehensive understanding of the actual weaknesses present in the educational plans and follow-ups. Specific interventions in the determinants of poor perceived health status may be useful for achieving the most favourable outcomes in the GUCH/ACHD

population, as has been previously described for other chronic conditions, such as diabetes and acquired heart diseases.^{4–7}

Thus far, the determinants of perceived health status among GUCH/ACHD patients remain poorly described on a global scale, despite their possible influence on the patients' overall adherence to follow-ups and, consequently, on patients' outcomes.⁸ In Italy, neither lifestyles nor determinants of perceived health status among GUCH/ACHD patients have been previously for large samples, thus undermining the possibility of planning mid-term and long-term strategies for patients who report poor perceived health or inadequate lifestyles. For these reasons, this study aimed to provide the first epidemiological lifestyle descriptions of the Italian GUCH/ACHD population by identifying the determinants of poor perceived health status.

MATERIAL AND METHODS

Design, study population and data collection

This cross-sectional survey was promoted by an Italian GUCH/ACHD centre and supported by the Italian Association of GUCH/ACHD (AICCA). The study design and reporting method aligned with the 'Strengthening the Reporting of OBServational studies in Epidemiology' checklist (online supplementary file 1). Data were collected through the list of contacts available in the AICCA's repository between March 2017 and October 2017. More precisely, data were collected using a computer/mobile-assisted, web interviewing survey, and participants were sampled via the repertory of contacts of AICCA contacts and stratified to reflect the geographical population by macro-area (ie, Northern, Central and Southern Italy).

According to the study protocol, all patients were informed on the study's aim and provided consent flagging an electronic form, whereas it was considered implicit due to their voluntarily and anonymously completion of the questionnaire.

Validation of the questionnaire on lifestyles

The development of this study's lifestyle questionnaire was based on a previous survey of the Italian National Institute of Public Health on the chronic disease population,⁹ adapted using a process of face and content validity to detect the peculiarities of GUCH/ACHD. Accordingly, the questionnaire's validation required the involvement of a multidisciplinary panel of experts (n=14) to ascertain the new questionnaire's face and content validity. The panellists (nine females; 35.7%) were aged a median of 44.6 years (IQR=7.4 years), had a minimum of 4 years of experience in CHD field, and comprised the following professions: cardiac surgeons (n=2), clinical nutritionists (n=2), clinical psychologists (n=2), clinical cardiologists (n=2), clinical nurses (n=2), experts of public health (n=2), experts in instrument development with a background in nursing at the doctoral level (n=2). Precisely,

face validity explored the panellists' understanding of each item and their comments about the overall concept they purported to measure through an assessment executed using open-ended questions. Conversely, content validity refers to the 'quantitative' agreement among panellists regarding how pertinent each item is in relation to the aim of its measurement.

Content validity encompassed the panellists' quantitative assessments using the content validity ratio (CVR), and the content validity index for item and scale level (I-CVIs and S-CVI). The CVR may potentially range between -1 (perfect disagreement among panellists) and +1 (perfect agreement among panellists), while I-CVIs and S-CVI range between 0 (no content judged as appropriate) and +1 (content totally judged as appropriate). As per the critical CVR cut-offs for determining adequate/inadequate content indices (ie, the lowest level of CVR such that the level of agreement was greater than 50%), recent research was proposed to consider critical CVR values as the statistics arising from binomial distribution that are applied to the panel sizes.¹⁰ A critical CVR value for 14 panellists is equal to 0.571¹⁰; as per I-CVIs, an adequate index must be equal or superior to 0.75, while S-CVI must be equal or superior to 0.70.¹¹

The first round of content validity was performed in June 2016 and was based on the questionnaire proposed by the Italian National Institute of Public Health.⁹ Thus, the panellists were asked to propose modifications insofar as adequate for developing a questionnaire for the specific GUCH/ACHD population. After four rounds of consulting the panellists and amending the questionnaire, all CVR values were higher than 0.65, I-CVIs were equal or higher than 0.80 and S-CVI was equal to 0.75. Further, the questionnaire was preliminarily tested on a small group of six patients to evaluate the clarity of each item. Patients were asked to respond to a 3-point Likert scale (1=completely not understandable, 2=somewhat understandable, 3=completely understandable) and an open-ended question to investigate the need for an eventual rewording of the terminology. We computed the Fleiss' kappa to determine the level of quantitative agreement between patients, which was 0.75 and indicated consensus in their defining of the questionnaire as understandable, although some minor amendments to the items' wording were requested as per the answers to the open-ended question. Finally, the questionnaire validation process was concluded in January 2017 (online supplementary file 2). The survey required roughly 30 min for its completion, and no respondent received compensation for participating in this study.

Measurements

The online survey collected the main socio-demographic and clinical characteristics of GUCH/ACHD patients, including their lifestyles and perceived health statuses.

Specifically, each participant's socio-demographic and clinical characteristics include sex, age, family composition, working role, educational background, provenience,

body mass index (BMI) and therapeutic plan. The lifestyles investigations revealed patients' dietary habits, substance use or abuse (eg, smoking, drugs) and physical and sexual activities. Conversely, their perceived health statuses were assessed using SF-12,¹² which has notably been successfully developed as a shorter version of the short form health survey 36 (SF-36) in nine European countries and demonstrates adequate validity in measuring the physical and mental components of health.¹² Thus, these components were respectively labelled physical component summary (PCS) and mental component summary (MCS), both of which were scored from 0 to 100 using the procedure indicated by the authors of reference, wherein a higher value indicates a more favourable health perception.¹² Further, it is possible to dichotomise the scores through an adequate versus an inadequate health perception if we consider the median split strategy¹³ and acknowledge that the median scores of general Italian population, clustered by different age ranges, were previously described.¹⁴

Statistical analysis

We calculated the response rate by considering the invitations sent to the contacts provided by the AICCA. All the collected variables were preliminary checked for possible missing data, outliers or errors using an analysis of frequency distribution. Categorical variables were described using frequency and percentage, while quantitative variables were assessed for normality via skewness and kurtosis analysis, followed by Shapiro-Wilk test. According to the quantitative variable distributions, we employed mean±SD or median and IQR to describe these variables. The univariate analysis was based on multiple comparisons of the lifestyles, ongoing treatments, PCSs and MCSs between the subgroups defined by the socio-demographic characteristics. According to the nature of each variable, the comparisons were performed using the following possible tests: χ^2 test or Fisher exact test (when appropriate), Mann-Whitney U test or Kruskal-Wallis H test (for non-normally distributed variables), t-test or one-way analysis of variance (for normally distributed variables). Variables exhibiting significant differences were evaluated to be used as predictors of inadequate PCS and MCS. A median split approach was used to dichotomise PCS and MCS,¹³ by considering the median values previously described among Italians aged between 18 and 44 years.¹⁴ Accordingly, PCS scores lower than 52.5 were considered as indicating inadequate physical health, while MCS scores lower than 51.2 were considered as indicating inadequate mental health. Subsequently, PCS and MCS were employed as dichotomous outcomes in two logistic regression (LR) models. The LR models were assessed for the possible collinearity between the independent variable by checking the strength of their bivariate associations, which should not exceed 0.45.¹⁵ Maximum likelihood estimation was used to determine the unknown LR model parameters through the generalised linear model function of R, while the goodness of fit as determined with the Hosmer-Lemeshow test (non-significant P indicates a

good fit), and Nagelkerke's pseudo- R^2 . The independent variables were simultaneously entered into the models to examine each variable's relatively unique contribution to health perception. Significance levels were set using $\alpha=5\%$. Overall, missing data referred to the socio-demographic section were managed using pairwise deletions, while no missing data were expected in the answering of the questionnaire, as all the questions were mandatory to complete the survey. Statistical analysis was run through Statistical Package for the Social Sciences V.22 (IBM Corporation) and R Statistical Package (R Foundation for Statistical Computing).

Patient and public involvement

Neither patients nor the public were involved in the designing of this research, although both will be informed of the survey results via the AICCA network. Accordingly, the authors will employ the AICCA's support to disseminate the study results.

RESULTS

The response rate was 89.7% (626 responses out of 698 invitations). Missing data were reported only for the provenience (n=3; 0.4%), BMI (n=1), education (n=3; 0.1%) and occupation (n=2; 0.3%). **Table 1** illustrates the participants' socio-demographic characteristics, lifestyles, ongoing treatments and health perceptions. Roughly one of every five patients (n=106; 18.1%) declared to be lowly adherent to their ongoing medical treatment. Patients were primarily treated with oral anticoagulants (n=162; 25.9%), antiarrhythmic drugs (n=121; 19.3%), diuretics (n=104; 16.6%), antiplatelet therapy (n=87; 13.9%), antihypertensive drugs (n=81; 12.9%) and dietary supplements (n=160; 25.6%).

The physical health (PCS12) scores reached a mean (SD) equal to 48.69±8.96, which was higher than that of mental health (MCS12; 45.56±10.99). Overall, the adequate physical and mental health scores were 53.6% (n=337) and 63.8% (n=401), respectively.

Differences of the variables described in **table 1** between adequate and inadequate physical health were significant considering diuretics ($\chi^2=22.9$; d.f.=1; p<0.001), antiarrhythmic drugs ($\chi^2=28.1$; d.f.=1; p<0.001), anticoagulants ($\chi^2=21.2$; d.f.=1; p<0.001), antiplatelet drugs ($\chi^2=11.1$; d.f.=1; p=0.001), antihypertensive drugs ($\chi^2=10.4$; d.f.=1; p=0.001), BMI ($\chi^2=8.4$; d.f.=3; p=0.033) and age (t=4.1; d.f.=610; p<0.001). Conversely, differences of the same variables between adequate and inadequate mental health were significant considering diuretics ($\chi^2=20.1$; d.f.=1; p<0.001), antiarrhythmic drugs ($\chi^2=22.7$; d.f.=1; p<0.001), anticoagulants ($\chi^2=19.2$; d.f.=1; p<0.001), antiplatelet drugs ($\chi^2=10.2$; d.f.=1; p=0.002), antihypertensive drugs ($\chi^2=9.4$; d.f.=1; p=0.003) and age (t=-2.3; d.f.=610; p=0.011).

As **table 2** indicates, the odds of inadequate physical health perception increased by more than two times in patients receiving antiarrhythmic therapy (OR adjusted=2.045; 95% CI=1.201 to 3.479; p=0.008; n=629), more than

Table 1 Descriptive characteristics of socio-demographics, lifestyles, ongoing treatment and health perception (n=629)

	n	%
Socio-demographic characteristics		
Sex		
Male	290	46.1
Female	339	53.9
Provenience		
Northern Italy	231	36.90
Central Italy	223	35.60
Southern Italy	172	27.50
Age		
Years (mean; SD; range: 18–57)	35.69	13.49
Body mass index (BMI)		
Kg/m2(mean; SD)	23.18	4.07
Underweight (BMI <18.5Kg/m2)	68	10.9
Normal weight (BMI: 18.5–24.9Kg/m2)	373	59.4
Overweight (BMI: 25–29.9Kg/m2)	145	23
Obese (BMI >30Kg/m2)	42	6.7
Offspring		
Yes	208	33.2
Education		
Lower or equal to high school	490	78.3
University education	136	21.7
Occupation		
Manager	32	5.1
Office worker	263	42
Student	113	18.1
Freelance	84	13.4
Unemployed	110	17.6
Retired	25	3.8
Lifestyles		
Smoking		
Yes	65	10.4
Illicit drugs		
Occasionally	81	12.9
Cannabis (occasionally consumer)	77	12.3
Cocaine (occasionally consumer)	2	0.3
Regular physical activities		
Yes	325	52.1
On daily basis	53	8.5
Two to three times per week	247	39.4
Once per week	40	6.4

Continued

Table 1 Continued

	n	%
Reasons to avoid regular physical activities		
Ill-judged	21	3.4
Lack of willing	139	22.2
Lack of energy	50	7.9
Fear	93	14.8
Daily time spent walking		
Less than 30min	285	45.5
Between 30 and 60 min	340	54.3
More than 60 min	154	24.6
Perception of adequate daily physical activities		
Yes	285	45.5
Sexuality education		
Never received	6	0.9
Poorly received	21	3.5
Sufficiently received	122	19.5
Adequately received	477	76.1
Contraceptive		
Yes	238	40.5
Low adherent to the ongoing medical treatment		
Yes	106	18.1
Ongoing treatment		
Medical therapy		
Diuretics	104	16.6
Antiarrhythmic therapy	121	19.3
Anticoagulants	162	25.9
Antiplatelet	87	13.9
Antihypertensive therapy	81	12.9
Dietary supplements	160	25.6
Health perception		
Physical health		
Score (mean; SD)	48.69	8.96
Mental health		
Score (mean; SD)	45.56	10.99
Adequate physical health (yes)*	337	53.6
Adequate mental health (yes)*	401	63.8

*Adequate physical and mental health were calculated using the median split, based on the Italian median scores of the study of the IQOLA Project (median score of physical health in general population was equal to 52.5; median score of mental health was equal to 51.2).

1.5 times in patients receiving oral anticoagulants (OR adjusted=1.638; 95% CI=1.038 to 2.585; p=0.034; n=629) and roughly 1.7 times in patients treated with antiplatelets (OR adjusted=1.743; 95% CI=1.024 to 2.966; p=0.041;

Table 2 Determinants of inadequate scores of PCS12 (outcome)

	Wald's χ^2	d.f.	P value	eb	95% CI
Predictor					
Constant	15.21	1	0		
Age	1.382	1	0.24	0.991	0.976 to 1.006
BMI	0.134	1	0.714	0.991	0.946 to 1.039
Diuretics	2.658	1	0.103	1.576	0.912 to 2.725
Antiarrhythmic	6.951	1	0.008	2.045	1.201 to 3.479
Anticoagulants	4.499	1	0.034	1.638	1.038 to 2.585
Antiplatelet	4.197	1	0.041	1.743	1.024 to 2.966
Antihypertensive	2.198	1	0.138	1.546	0.869 to 2.75
Model fit					
	χ^2	d.f.	P value		Pseudo-R ² (Nagelkerke)
Likelihood ratio test	16.3	9	0.049		0.236

BMI, body mass index; PCS12, physical component summary.

n=629). Conversely, as per [table 3](#), the odds of inadequate mental health perception increased by roughly 2% for each year a participant aged (OR adjusted=1.017; 95% CI=1.002 to 1.032; p=0.025; n=629).

DISCUSSION

This study represents the first overview in Italy of ACHD/GUCH patients' lifestyles by identifying determinants of poor perceived health status. Our results are strategic considering that they allow a comparison between the general population's lifestyles and those of ACHD/GUCH patients. These possible comparisons are particularly worthy considering that the majority of patients born with CHD are expected to survive into adulthood, being exposed to the general risks of inadequate lifestyles (ie, modifiable cardiovascular risks).¹⁶ Further, this

study contributes to identify potentially important determinants of poor physical and mental health and focuses attention onto patients who present those determinants.

This study highlights that associations exist between antiarrhythmic drugs, oral anticoagulants, antiplatelet drugs and lower physical health status. To the best of our knowledge, this study provides the first empirical evidence of these associations in the GUCH/ACHD population. Previous research has demonstrated similar results in patients with paroxysmal atrial fibrillation, wherein patients treated with antiarrhythmic drugs reported lower physical health than did patients treated with radiofrequency ablation.¹⁷ Even if the literature does not fully address the question of whether or not physical health is directly associated with antiarrhythmic drugs in patients with atrial fibrillation,¹⁷ there is room

Table 3 Determinants of inadequate scores of MCS12 (outcome)

	Wald's χ^2	d.f.	P value	eb	95% CI
Predictor					
Constant	1.437	1	0.231		
Age	5.038	1	0.025	1.017	1.002 to 1.032
BMI	1.784	1	0.182	0.968	0.924 to 1.015
Diuretics	0.248	1	0.619	1.142	0.677 to 1.925
Antiarrhythmic	0.683	1	0.409	1.241	0.744 to 2.07
Anticoagulants	0.462	1	0.497	1.17	0.744 to 1.838
Antiplatelet	0.019	1	0.891	0.965	0.581 to 1.603
Antihypertensive	0.012	1	0.913	1.031	0.595 to 1.787
Model fit					
	χ^2	d.f.	P value		Pseudo-R ² (Nagelkerke)
Likelihood ratio test	16.3	9	0.049		0.135

BMI, body mass index; MCS12, mental component summary.



in the clinical practice for monitoring the physical health trajectories of patients treated with antiarrhythmic drug over time. Similar associations with a decreased quality of life and physical health were described in patients treated with anticoagulants and/or antiplatelet drugs,¹⁸ even if little is currently known in GUCH/ACHD population about the effects of these drugs on physical and mental health statuses.¹⁹ These associations should be studied in future research, and possible manifestations of side effects should be monitored to understand whether the worsening of one's physical health is related to the drug-related side effects or other factors, such as the psychological burden related to one's need for medical therapy in terms of posology and adherence.

As described above, our results profile patients who are at greater risk for achieving inadequate physical health in consideration of their ongoing treatments. Conversely, mental health status seems to worsen as individuals age, which may be related to many GUCH/ACHD patients' previously described fear of ageing, that is enhanced by a sense of uncertainty²⁰; in other words, the GUCH/ACHD population's psychological needs increase with age.

An unexpected result was related to the rates of reported physical activities, which were consistent with those described for the general population.²¹ Our initial expectation was to identify a lower rate of physical activity in GUCH/ACHD patients, because past clinicians restricted patients' activity due to concerns that increased activity might be risky for patients' health.²² Over the last 10 years, the recommendations from a consensus of an international expert panel endorsed by the European Society of Cardiology encourage that all CHD patients regularly exercise; while these recommendations are mainly based on expert opinion, there nevertheless exists scarce evidence for the effects of exercise training.²³ Our results confirm the shifting of paradigm from the restriction of physical activities to its support of educational advices. Accordingly, the steady progress in GUCH/ACHD diagnostics emphasise the life-long benefits of regular physical activity for general health as well as in complex CHD (adequately adherent to the follow-ups).²⁴

Overall, our sample reported an adequate BMI that was slightly lower than previous epidemiological, self-report BMI assessments of the Italian general population aged between 30 and 45 years.²⁵ The other socio-demographic characteristics are consistent with the current data regarding general population.^{25 26} Concerning lifestyles, the rate of smokers among the GUCH/ACHD sample (10.4%) appears to be encouragingly lower than that reported in general population (21.4%)²⁷ as well as that determined by a recent description in Malta.²⁸ This result may be related to the clinicians' high sensibility when providing regular anti-smoking advice and education. Cannabis consumption, on the other hand, appears to be consistent with and slightly higher than the general population's rate of self-reported consumption.²⁹ This result is also in line with previous evidence of younger adults with CHD, whose behaviours were described as being

more strongly influenced by peer relationships than the awareness of one's clinical condition.³⁰ Clinicians should address this aspect with increasing attention to reduce illicit drug consumption by administering to the GUCH/ACHD population detailed information that highlights the risk of increased systolic blood pressure, orthostatic hypotension and ischaemic stroke.³¹

Limitations

This study's findings are subject to some important limitations. First, the impossibility of collecting reliable clinical data (eg, CHD classification, diagnostics) undermined the possibility of drawing solid, inferential associations between lifestyles (behaviours) and clinical outcomes. For this reason, this study has mainly provided descriptive information to frame new knowledge of the Italian GUCH/ACHD population's lifestyles. Second, we suspect the possibility that the levels of risky behaviours were underestimated and the levels of healthy behaviours were overestimated according to the potential social desirability effect's occurrence in the participants' responses. However, the choice to anonymously collect data should have limited the probability that the social desirability effect would occur. Third, data collection was performed using the AICCA network, which may have introduced a bias in the sampling procedure because patients from the AICCA — that is, patients who have learnt skills of observation, description and symptom handling, thus increasing their basic knowledge of health problems — may have more likely been 'activated' than general patients and because they were not representative of the general population. We believe this sampling bias is generally marginal in this study, as the AICCA holds the contacts of real-world patients from the majority of CHD centres in Italy, and not all patients in the AICCA network actively participate in the association's initiative. Fourth, this study has included no information on the possible manifestations of drug-related side effects or other factors that may interact through the relationship between drugs and physical health, which such information might help effectively interpret. Overall, considering this study's limitations, we suggest that caution be taken when generalising the results. This study's strengths are related first to the fact that patients roughly equally represent Northern, Central and Southern Italy and second to the prudent approach used to analyse the data.

CONCLUSIONS

Thus far, this study represents the first lifestyle descriptions of the Italian GUCH/ACHD population, and we have identified a number of similarities and differences among the general Italian population. Clinicians should address the issue of illicit drug consumption (especially cannabis) more deeply, and particular attention should be paid to accommodating the increasing psychological needs resulting from these patients' age progression. More research is needed to identify the associations

between lifestyles and clinical outcomes to determine additional details for homogeneous subgroup stratifications in consideration of patients' clinical information, such as CHD classification.

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Contributors RC, FD, CA, SFF, AG and MC: conception and design. FD, SFF, AG and MC was particularly involved in the acquisition of data; RC and CA in analysis and interpretation of data. RC, FD, CA, SFF, AG and MC have substantially contributed in drafting the manuscript and in providing critical revision of important intellectual content. Each author gave their final approval of the version to be published. Each author should have participated sufficiently in the work to take public responsibility for appropriate portions of the content.

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Competing interests None declared.

Patient consent for publication Obtained.

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